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R E V I E W

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The 1st Annual Awards for Action on HIV/AIDS and Human Rights

The 1st Annual Awards for Action on HIV/AIDS and Human Rights were awarded to the Vancouver Area Network of Drug Users and to Dr Wan Yanhai, a Chinese physician and activist.¹ The international attention and media coverage of the awards was heightened by the fact that the Chinese government had detained Dr Wan for disclosing information about unsanitary blood collection practices in Henan province. An international outcry led to Dr Wan's release on 20 September 2002.

On 13 September 2002, the 1st Annual Awards for Action on HIV/AIDS and Human Rights were presented in Montréal. The sponsors of the awards include the Canadian HIV/AIDS Legal Network, Human Rights Watch, the International Harm Reduction Development Program, the Hilda Mullen Foundation, and Mark Gallop. They are intended to highlight outstanding work by individuals

and organizations to decrease vulnerability to HIV/AIDS and protect the rights and dignity of those infected and affected. The recipient of the first Canadian award was the Vancouver Area Network of Drug Users (VANDU). The recipient of the first International award was Dr Wan Yanhai, founder and coordinator of the AIZHI (AIDS) Action Project in China.

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Legal, Ethical, and Human Rights Issues at Barcelona 2002

At the XIV International AIDS Conference in Barcelona, Spain, in July 2002, legal, ethical, and human rights issues were once again prominent. For the second conference in a row, there was a special track devoted to advocacy and policy issues (Track G), and a full-day satellite meeting on human rights issues. One issue in particular – the inadequacy of the current response – permeated Track G and all of the other tracks as well. The conference produced a consensus that effective action to deal with HIV/AIDS is urgently required. Delegates expressed frustration at the gap between what is possible and what is happening now.

In this special section of the Review, with funding from UNAIDS, we reproduce some of the most relevant presentations on legal, ethical, and human rights issues given at the conference and at the satellite meetings.

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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.

Contributions are welcome and encouraged. Please contact Anne Renaud at the following address to discuss your article and to obtain a copy of our style guide:

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Canadian HIV/AIDS Legal Network

The Network is a charitable organization engaged in 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.

Comments?

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

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EDITORIAL

This year the **Canadian HIV/AIDS Legal Network** is marking its 10th anniversary. In the previous issue of the *Review* the Hon Justice Michael Kirby offered an editorial on what we have learned and what we have yet to learn about the HIV epidemic. In this issue we continue these editorial reflections with an abridged version of the keynote speech that David Hoe gave at the Network's Annual General Meeting in September 2002. His speech was a moving, perceptive, and challenging assessment of the lives of Canadians with HIV/AIDS and of language that is true to such lives. The full text may be found on the website of the Network at www.aidslaw.ca by clicking on "Main Content" and "Events."

Legal and Human Rights Challenges for People Living with HIV/AIDS: A Personal Perspective

I wish to address, as a person living with HIV/AIDS, some of the constructs I see leading to legal and human rights challenges for people living with HIV/AIDS. My premise is that every one of us faces legal or human rights challenges. Of course, this has little to do with our infections alone. These challenges are formed mainly by people who are not living with HIV. Their experiences determine the perception of us in society. This is where our challenges take shape, through the eyes and beliefs of others, some of whom have been dead for a century or more and who live on through systemic prejudice.

The Realities of People Living with HIV

We Canadians living with HIV/AIDS – who are we and what do we witness? It is most common to hear ourselves described from an epidemiological point of view. Sometimes we are known by our identity, sometimes we are known by the way we became infected, sometimes we are known because of our cultural roots, sometimes we

are known because of our practices and behaviours. None of these categories describe us at all closely. They are categories to aid planning and organizing, principally for HIV prevention, or to guide research, or to facilitate clinical control over illness.

We who live with HIV/AIDS must also be regarded differently because this is our life story, and in this story lies the root system of our infections, of our abilities to live with the disease, of our own definitions and analysis of what is needed for survival, and of who we are beyond and before HIV/AIDS – and because this is how we will understand the contexts for our legal and human rights challenges.

Let me give you just a few examples, not at all inclusive of all people living with HIV/AIDS. It is in these lives that the legal clinic for people with HIV in Ottawa sees housing discrimination as the most common concern brought forward. It is in these lives that women face an interminable battle of safety and security in their relationships,

when power and sex is dangerously controlled by men not conscious of how power and gender issues affect them too. It is in these lives that people in prison face complex decisions and relationships with people and prison systems. It is in these lives that people wrangle alone with injection drug use. It is in these lives that the sword of justice swooped over our heads in the *Cuerrier* decision, and rested potential criminality on the shoulders of all Canadians living HIV/AIDS, from the youngest to the oldest.

The False Character

Those of us who have lived the epidemic over the years have grappled with survival in a society that has not, of spontaneous free will, come forward through its institutions, systems, and leaders to show the finer values of society – values such as equal worth, care without comparison, and inclusion.

Instead, fear and shame took centre stage. Not the fear within those with the disease, or their shame, but the fear of those with the power to lead and determine opinion. This void, this state of distance, this gulf of denial, became systematized, gathered momentum rapidly and, because of its massive authority, quickly became familiar and gathered status. That early beginning determined the false character of the person with HIV/AIDS, and became the base for all our contemporary legal and human rights challenges. Since then, in every aspect of life for people with HIV, a discriminatory and stigmatized world has been ours to deal with. The act of discrimination, or of bestowing stigma specific to HIV and AIDS, has little to do with our infection and all to do with the fears of others.

The Role of Language

Paula Treischler says “AIDS is not merely an invented label, provided to us by science and scientific naming practices for a clear disease entity caused by a virus. Rather, the very nature of AIDS is constructed through language.”

The language of our experience is, most frequently, that of statistical data and science. But I think that this language is too incomplete and underdeveloped to describe the world of the person with HIV/AIDS, and is of only partial use regarding our legal and human rights challenges. Statistics are good for planning and projecting, but alone they do not carry us to action.

Goethe, the German philosopher, points to an alternative. He writes, “It is no great matter to make a goddess into a witch, or a virgin into a harlot; but to achieve the

contrary, to give the humiliated dignity, to make the fallen worth coveting, for that either art or character is needed.”

While I would love to discuss the power of the aesthetic, I will take Goethe’s other requirement, that of the need to invoke character. Here, I turn to James Joyce, the Irish writer. His character Stephen, as he leaves Ireland, says, “I go ... to forge in the smithy of my soul the uncreated conscience of my race.” When Joyce wrote those words, he pointed us to a relationship between the soul and the forge. Both are places where the elements get merged, where transformation takes place, and where fire prepares one form with shape and character to be reshaped.

Creating the conscience of our race equates to creating a consciousness for our work, which in turn creates a just character for people living with HIV/AIDS.

I often get asked why AIDS work is so hard. I believe it is because we are both fire and forge. The fire is the intense energy we infuse into our work. The forge is human, in the sense that we work on ourselves at all levels. We must expect sparks to fly when we are concerned with change and with altering the false character of people living with HIV/AIDS that is determined by prejudice and stigma.

What language would speak to the lives of those of us with HIV/AIDS and our human rights and legal challenges? It is the language that precedes the law and precedes the need to have human rights challenges. We need to have language that deals with the whole and that enhances the integration of people’s experiences; language that permits the continued identification of issues; language that elicits hope and promise; and language that sits well in the soul.

For those of you who have seen the roller coaster of HIV/AIDS, you will know that there are myriad situations for which there is yet to be a remedy or solution. We all know this, but how much easier it is to manage when the values, words, and actions are true to our experiences. Even death can be managed with empowerment and magnificence when the whole self can be present. In the absence of consciousness and meaningful language, we are left with rage, raw experience, and dark humour. All of which, if not brought to consciousness and rightful place, turns life back on itself.

The Contribution of the Legal Network

Out of necessity and awareness, the Legal Network was born 10 years ago to be a generator of the analysis of this deeper language. Building on the work of earlier AIDS activists, the Legal Network is now one of the symbols of

Goethe's call for character and Joyce's smithy of the soul – one of our national bodies working to enable the accurate character of who we are, as Canadians living with HIV/AIDS in a global context.

The Legal Network took on this consciousness raising, this reworking of language, this character description. Over the last 10 years, it has brought an organized community, a legal, ethical, and human rights policy lens into the Canadian context, and in large part has enabled many of us to change our language and consciousness. What is wonderful is that the ideas challenge us all, whether we are infected with HIV or not. The work expands beyond its intentions. This is part of the language. It strengthens everyone's life, for we are not separate, no matter how much we may try.

As I look at the current human rights and legal challenges for Canadians with HIV/AIDS, I believe that past vigilance will need to continue. I will focus on three challenges: the right to information; the right to treatment and care; and the right to purposeful activity, such as work and education.

The Right to Information

I want to talk about HIV disclosure, an area where the lack of information on multiple issues has painful consequences, sometimes catastrophic. Of all the issues likely to rile me, HIV disclosure is the one most likely to do so. My personal intensity is influenced by my own difficulties with this in some situations. I am astounded that, for the most part, people with HIV are deprived of information and skills to enable them to become resourceful at disclosing their HIV status to others. This is a straightforward, lifetime disease-management component.

No disclosure of HIV status is without risk to privacy, denial of rights, and potential loss of intimacy. (Intimacy, that meaningful connection with others at all levels, is one of the most undervalued aspects in the analysis of life with HIV and AIDS. Now, subsequent to the *Cuerrier* decision of the Supreme Court, it is in the realm of criminal law.) The empowered and spiritually strong statements, "I am HIV-positive" or "I have AIDS," only happen when internal safety can withstand outside prejudice. These statements thrive as personal statements when they claim power over all that I have discussed. It is, of course, part of managing the job of being a person with HIV and AIDS.

The Right to Treatment and Care

We are still a long way from assured treatment and care for all. Here again, we see portrayed the false character of

the person whose rights have been denied. Some of the terms used that signal the false character raise my hackles, and I reject them as part of our character – terms such as non-compliant, non-adherent, and complacent. They point to the person as a failure. They do not convey that the treatment and care is not yet manageable, accessible, or available. The best treatment and care is available to people who live near an HIV clinic, who have a general practitioner skilled in HIV care, who have a drug benefits plan with low administrative requirements, who do not use illicit substances, who have organized lives, who have a safe home, and who are willing to take the risk of disclosure. Given who many of us are, the right to the best treatment and care is not met.

The Right to Income, Employment, and Purposeful Activity

The right to income, employment, and purposeful activity is strongly linked to insurance disability programs, rehabilitation programs, and workplaces with appropriate accommodation policies and practices. Sustaining work, education, or meaningful activity requires accommodation. Insurance programs, which could bolster the stability of someone over the long term, are generally suspicious of spasmodic or restrictive conditions that are not permanently severe. This, of course, forces people to make less empowering choices.

Rehabilitation programs are generally regarded as a luxury, and are not yet integrated into our service plans, unless one is recovering from physical disability. Much of the experience of managing the disease has to do with managing the unpredictable, and with the diversity of manifestations, sometimes short-term, sometimes long-term. Without a context in which to understand this, and to develop skills in this, the experience becomes, in and of itself, draining. Rehabilitation can provide this context.

Greater Than These . . .

Is this all dismal? Absolutely not. Greater than the challenges is the resolve – the resolve to continue to build the true character of the person with HIV/AIDS, that of someone who is able to learn to manage the disease and define changing needs; who manages uncertainty; who sees him- or herself as part of a greater picture of life; who is but potential; and who, at any point, can start to determine self-direction.

There are no benefits to AIDS, but there are benefits from our experiences of AIDS, and from AIDS as the language, not the disease. We do determine what we make of

those experiences, what meanings we attach to them, and how they inform our actions. This is true for those of us living with the disease, for those in service with us, and for those in positions of leadership. This will be the testament to our human capacity for compassion and justice.

– *David Hoe*

David Hoe is a person with HIV/AIDS who has a long history of involvement with HIV/AIDS. He is a senior policy advisor on HIV/AIDS with Health Canada, current member and past Co-Chair of the Ontario Advisory Committee on HIV/AIDS, and a past Executive Director of the AIDS

Committee of Ottawa. He was a founding member of the Ottawa-Carleton Coalition of People Living with HIV/AIDS. He has served on a number of local, provincial, and national community boards and committees for HIV/AIDS, queer issues and services, and other community interests.

FEATURES

House of Commons Committee Releases Report on Canada's Drug Strategy

On 17 May 2001, the House of Commons created a Special Committee on Non-Medical Use of Drugs based on a motion introduced by Randy White, Canadian Alliance MP (Langley–Abbottsford) and gave it a very broad mandate to study “the factors underlying or relating to the non-medical use of drugs in Canada” and to propose recommendations aimed at reducing “the dimensions of the problem involved in such use.” In December 2002, the Committee released its report, entitled *Policy for the New Millennium: Working Together to Redefine Canada's Drug Strategy*.¹ The report contains many good recommendations, but fails to deal adequately with the fundamental harms caused by Canada's drug laws and federal government inaction. Far better is the supplementary report written by NDP MP Libby Davies (Vancouver East), which contains an excellent, informed critique of the report. The supplementary report from the official opposition, written by MPs Randy White and Kevin Sorenson (Crowfoot, Alberta) also makes for interesting, if troubling, reading - it is based nearly exclusively on fiction rather than facts and science.

The Committee's report is yet another in a list of reports on drug policy in Canada that is becoming longer and longer,² while government action continues to be slow - although more recently we have been seeing some promising signs, such as the Minister of Health's willingness to consider applications for supervised injection sites (described in the article immediately following this one).

In preparing its report, the Committee met with more than 200 individuals (researchers, academics, treatment providers, policy experts, and volunteers) at hearings across Canada. The Committee also received written submissions from many

groups and individuals. Finally, it visited treatment centres and “low-threshold services” across Canada, “inspected some of the busiest border control facilities in Canada, and traveled to the United States and Europe in order to consult with addiction experts, research institutes, politicians, law enforcement agencies, and senior government officials, and to experience first-hand, the impact of some of their more innovative treatment regimes.”³

During its meetings and visits, the Committee heard evidence relating to a host of licit and illicit substances, as well as the people most affected by them. The report says: “Three decades

after the final report of the Le Dain Commission, the Committee was shocked and saddened to learn that the associated health and social devastation continues, to the extent that substance abuse is linked to one in five deaths in Canada.”⁴

Issues and Recommendations

The report contains nine chapters:

1. Mandate of the Committee
2. Use and Harmful Use of Substances, and Dependence in Canada
3. Canada's Drug Strategy
4. Research and Knowledge
5. The Use and Harmful Use of Substances: Public Health Issues
6. Substance Use and Public Safety
7. International Treaties and Legislative Reform
8. Drug Policies Abroad
9. Cannabis

“The Government of Canada should take immediate action to ensure that a well-funded federal drug strategy will be in place by summer 2003.”

The following text briefly reviews some of the most important issues addressed in these chapters and some of the report's 41 recommendations (see the article on HIV/AIDS in Prisons: Recent Developments in this issue of the *Review* for comments on chapter 6, Substance Use and Public Safety, which contains recommendations concerning the prison system).

Canada's Drug Strategy

Chapter 3 provides a historical overview of Canada's Drug Strategy, and concludes that "investing in a renewed Canadian drug strategy is critical and will contribute to reducing the demand for, and consequently, the supply of substances, as well as reducing the spread of infectious diseases and the social and health costs associated with the harmful use of substances."⁵ Therefore, the Committee says, "[t]he Government of Canada should take immediate action to ensure that a well-funded federal drug strategy will be in place by summer 2003."⁶ Specifically, the Committee recommends that

- "the Government of Canada reaffirm its commitment to addressing the use and harmful use of substances and dependence, by developing, in consultation with provincial/territorial governments and key stakeholders, a renewed, comprehensive, coordinated and integrated Canadian drug strategy to address the use of illicit substances and licit (or legal) substances such as alcohol, tobacco, inhalants and prescription drugs";⁷
- a "Canadian Drug Commissioner" be appointed and be "statutorily mandated to monitor, investigate and audit the implementation of a renewed Canada's

Drug Strategy and to report and make recommendations annually to Parliament, through the Speaker of the House of Commons";⁸ and

- the Canadian Centre on Substance Abuse, "as an independent non-governmental organization, be given the mandate to develop, in consultation with federal, provincial and territorial governments and key stakeholders, the goals, objectives, the performance indicators and the strategic plan for a renewed Canada's Drug Strategy."⁹

"Politicians and policymakers continue to direct the overwhelming majority of resources into failing supply-reduction strategies, despite the wealth of scientific evidence demonstrating their ineffectiveness."

In her supplementary report, MP Libby Davies supports these recommendations, but points out that the crux of the matter will not be whether a federal Drug Strategy will be funded, but whether the Strategy will finally provide adequate support for treatment, prevention, and harm reduction. She says:

The 2001 Auditor General's report on Illicit Drugs sharply focused on the weakness, lack of accountability and failed implementation of Canada's Drug Strategy. The primary focus of that strategy *in practice* has been on enforcement – the use of

what are essentially criminal law powers to deal with drugs. This focus on interdiction ("supply reduction") has drawn resources away from other measures that could be far more effective in reducing substance misuse and its related harms.

The emphasis on criminal prosecution for behaviour linked to illicit drug use has not decreased use nor effectively dealt with serious health and safety issues. In fact, there is substantial expert evidence that prohibitionist policies and criminalization of drug users *increases* the harms associated with drugs. Drugs lack quality controls, education may be skewed because of the illegal status of drugs, and the expense of buying drugs on the illegal market may encourage users to take drugs in a manner that increases health risks. This greatly increases the risk of harm from disease and overdose. The report fails to distinguish harms that may flow from the pharmacology of the drug from harms that may flow from the policies, such as prohibition and inadequate education.¹⁰

A recent study by Wood et al also raises serious questions about the current emphasis on supply-side interventions to control the drug use epidemic in Canada.¹¹ The study observed no beneficial public health effects of Canada's largest-ever heroin seizure – the seizure had no significant effect on the supply of heroin. The authors severely criticize politicians and policymakers "who continue to direct the overwhelming majority of resources into failing supply-reduction strategies, despite the wealth of scientific evidence demonstrating their ineffectiveness."¹² They conclude that "[o]ur findings support the strong consensus

that curbing the HIV and overdose epidemics will require a shift in emphasis toward alternative strategies based on prevention, treatment and harm reduction, even if this shift necessitates a diversion of resources away from criminal justice interventions.¹³

Public Health Issues

The chapter on public health issues starts with an acknowledgment that “the use and harmful use of substances are primarily public health issues”; that some Canadian urban centres are “the scenes of ... public health disasters”; that the “public health crisis is on-going and cannot be ignored”; and that “prevention, education, treatment and rehabilitation, and harm reduction are all elements of an integrated approach based on a public health model that must be implemented to address this crisis.”¹⁴

The chapter contains 16 recommendations relating to prevention and education, treatment and rehabilitation, and harm reduction. Most of the recommendations are consistent with those made in other reports and are not new.¹⁵ Nevertheless, it is significant that a parliamentary committee has now endorsed them. Among them are the following recommendations:

- “that the Government of Canada, under a renewed Canada’s Drug Strategy, provide sustained funding and resources to develop and implement health-based public awareness, prevention and education programs related to the use and harmful use of substances, and dependence, in collaboration with provincial, territorial and municipal authorities, and community-based organizations”;¹⁶

“If drug misuse is a public health issue, why do the police deliver drug education programs?”

- that a renewed Drug Strategy “explicitly recognize the concept of and contribute toward a continuum of care, including low-threshold services, long-term treatment and recovery services”;¹⁷
- that the proposed clinical trial pilot project in Vancouver, Toronto, and Montréal to test the effectiveness of heroin-assisted treatment be implemented;¹⁸
- that the Government of Canada remove any federal regulatory or legislative barriers to the implementation of scientific trials of supervised injection sites;¹⁹ and
- that Canada’s Drug Strategy “identify harm reduction as a core component of Canadian drug policy.”²⁰

While she expresses strong support for these recommendations, Davies points out in her supplementary report that the Committee downplays or misses fundamental points with regard to drug education. She asks:

If drug misuse is a public health issue, why do the police deliver drug education programs? The police are qualified to discuss the law concerning illegal and legal drugs, but they are not pharmacologists or public health officials. There is substantial evidence that current drug education programs conducted by the police are ineffective.²¹

She continues by saying:

Even if these flaws in current drug education programs did not

exist, the police are constrained in the type of education they can give. Their job is to enforce the law. Some police may object to providing education on safe use practices, since they may view that as contradicting their role in enforcing the law against users. Yet by failing to provide education about how to use as safely as possible we abandon the many millions of Canadians who at some point use illegal drugs. While it is essential to discourage Canadians from harmful drug use, it is equally important to minimize the dangers for those who do, by giving honest, factual and non-judgmental education. Such education can save lives and protect the health of both users and the communities around them. There is a critical need for health-based, realistic education and prevention, targeted to key groups who are at risk, such as youth, that promotes safety, health and well-being of individuals and the community as a whole.²²

Cannabis

With regard to cannabis, the Committee issued two recommendations:

- that the possession of cannabis continue to be illegal and that trafficking in any amount of cannabis remain a crime; and
- that the Minister of Justice and the Minister of Health establish a comprehensive strategy for decriminalizing the possession and cultivation of not more than thirty grams of cannabis for personal use.²³

These recommendations provide a step in the right direction, but Davies points out that decriminalization is only a partial solution and suggests

that, instead, the government should implement the recommendations in the report of the Special Committee on Illegal Drugs of the Senate of Canada, entitled *Final Report: Cannabis: Our Position for a Canadian Public Policy*²⁴:

Decriminalization of possession and cultivation of small amounts, as recommended by the Committee, would prevent such users and cultivators from receiving a criminal record. However, it still leaves intact the other harms associated with our current system of criminal prohibition. Among them, simply handing a “joint” to a friend would continue to constitute the offence of “trafficking” under the *Controlled Drugs and Substances Act*. The intrusive police powers given by the Act would likely remain.

Furthermore, the Committee’s proposal does nothing to address the situation of those saddled with a criminal record for simple possession or for transfer or cultivation of small amounts for non-commercial purposes. If we accept that Canadians should not in future receive a criminal record for certain acts relating to marijuana, those convicted in the past should be pardoned under a general amnesty, and their records erased.²⁵

Davies concludes:

There has already been extensive public debate on the use of mari-

juana, decriminalization, and legalization. The NDP appreciates the Senate Special Committee Report on Cannabis that raises rational and significant questions. The federal government should consider their analysis and recommendation for a criminal exemption scheme. The NDP urges the federal government to investigate and introduce non-criminal and non-punitive regulatory approaches for adult use, as a preferable direction of public policy, emphasising the need for realistic education and harm prevention programs.²⁶

Finally, Davies points out that the House of Commons Committee on the Non-Medical Use of Drugs did not deal with marijuana for medical use, and refers to the recommendations of the Senate Special Committee on Illegal Drugs in this regard.

– Ralf Jürgens

Ralf Jürgens is the Executive Director of the Canadian HIV/AIDS Legal Network. He can be reached at ralfj@aidslaw. A detailed review of new developments in the area of safe injection sites in Canada will be published in the next issue of the *Review*.

¹ Available at www.parl.gc.ca/InfoComDoc/37/2/SNUD/Studies/Reports/snudrp02-e.htm (page references are to pdf version, accessed by clicking on “Print Format”).

² See, eg, Canadian Centre on Substance Abuse & Canadian Public Health Association. *HIV, AIDS and Injection Drug Use: A National Action Plan*. Ottawa: The Centre & The Association, 1997 (available via www.ccsa.ca); Canadian HIV/AIDS Legal Network. *Injection Drug Use and HIV/AIDS: Legal and Ethical Issues*.

Montréal: The Network, 1999 (available at www.aidslaw.ca/Maincontent/issues/druglaws.htm); Elliott R, Malkin I, Gold J. *Establishing Safe Injection Facilities in Canada: Legal and Ethical Issues*. Montréal: Canadian HIV/AIDS Legal Network, 2002 (available at www.aidslaw.ca/Maincontent/issues/druglaws.htm); Federal/Provincial/Territorial Committee on Injection Drug Use. *Reducing the Harm Associated with Injection Drug Use in Canada*. Ottawa: 2001 (available at www.aidslaw.ca/Maincontent/issues/druglaws.htm); MacPherson D. *A Framework for Action: A Four Pillar Approach to Drug Problems in Vancouver*. City of Vancouver: 2001 (2nd, revised version).

³ Supra, note 1 at 2.

⁴ Ibid.

⁵ Ibid at 41.

⁶ Ibid.

⁷ Ibid at 44 (recommendation 1).

⁸ Ibid (recommendation 3).

⁹ Ibid (recommendation 5).

¹⁰ Ibid at 180.

¹¹ Wood E et al. Impact of supply-side policies for control of illicit drugs in the face of the AIDS and overdose epidemics: investigation of a massive heroin seizure. *Canadian Medical Association Journal* 2003; 168(2): 165-169.

¹² Ibid at 168, with many references.

¹³ Ibid, with many references.

¹⁴ Supra, note 1 at 61.

¹⁵ Supra, note 2.

¹⁶ Supra, note 1 at 69 (recommendation 12).

¹⁷ Ibid at 78 (recommendation 15).

¹⁸ Ibid at 79 (recommendation 20). For more details on the proposed trial, see Brissette S. Medical prescription of heroin - a review. *Canadian HIV/AIDS Policy & Law Review* 2001; 6(1/2): 1, 92-98.

¹⁹ Supra, note 1 at 89 (recommendation 23).

²⁰ Ibid (recommendation 25).

²¹ Ibid at 180.

²² Ibid.

²³ Recommendations 40 and 41.

²⁴ September 2002 (available at www.parl.gc.ca/common/Committee_SenRep.asp?Language=E&Parl=37&Ses=1&comm_id=85).

²⁵ Supra, note 1 at 182.

²⁶ Ibid.

HIV/AIDS in Prisons: Recent Developments

In a report released on 20 November 2002, entitled *Action on HIV/AIDS in Prisons: Too Little, Too Late – A Report Card*, the Canadian HIV/AIDS Legal Network concluded that despite repeated studies and nearly ten years of recommendations for urgent and pragmatic action, the response of Canadian governments to HIV/AIDS, HCV, and injection drug use in prisons remains inadequate. Only a few weeks later, the House of Commons Special Committee on Non-Medical Use of Drugs released its report, which contained a number of recommendations to the Correctional Service of Canada. Although the Committee avoided talking about needle exchange programs in prisons, it did recommend them! Meanwhile, in Ireland, not even condoms or bleach are provided. 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: Legal Network Releases Report Card

The prevalence of HIV/AIDS and hepatitis C in federal and provincial prisons continues to increase and Canadian governments are failing to provide the resources and leadership necessary to prevent the spread of infectious diseases among prisoners. In a new report released on 20 November 2002, entitled *Action on HIV/AIDS in Prisons: Too Little, Too Late – A Report Card*,¹ the Canadian HIV/AIDS Legal Network concludes that despite repeated studies and nearly ten years of recommendations for urgent and pragmatic action, government response remains inadequate.

Background

The issue of HIV/AIDS and prisons has been studied extensively in Canada² and internationally.³ Since 1992, a number of reports have been released in Canada providing recommendations to the federal and provincial/territorial governments about how

best to implement a comprehensive and compassionate response to the HIV/AIDS and hepatitis C (HCV) crisis in prisons.

In 1992, the Prisoners' HIV/AIDS Support Action Network (PASAN) released *HIV/AIDS in Prison Systems: A Comprehensive Strategy*.⁴ Shortly after the release of the PASAN report, the Correctional Service of Canada (CSC) created the Expert Committee on AIDS and Prisons (ECAP) to assist the federal government in promoting and protecting the health of prisoners and of staff, and preventing the transmission of HIV and other infectious agents in federal correctional institutions. In 1994, ECAP released a report with 88 recommendations.⁵

In 1996, *HIV/AIDS in Prisons: Final Report* was published by the Canadian HIV/AIDS Legal Network and the Canadian AIDS Society.⁶ The Final Report reviewed the history of the response to HIV/AIDS in prisons

since the release of ECAP's report, nationally and internationally; presented relevant new developments in the area; examined whether there is a legal and/or ethical obligation to provide prisoners with the means that would allow them to protect themselves against contracting HIV; and addressed the issue of the potential liability for not providing condoms, bleach, and sterile needles – and the resulting transmission of HIV in prisons. The goal was to assist CSC and provincial/territorial prison systems in their efforts to reduce HIV transmission in prisons and to staff and the public. The Final Report contained a list of recommendations for action that updated some of the recommendations made by ECAP. It concluded that “unless CSC and provincial [territorial] prison systems now act quickly and decisively, they may be held morally and legally responsible for the consequences of their inaction for

prisoners, staff, and the public.”⁷ The Report was submitted to both the federal and the provincial/territorial governments for response and action.

HIV/AIDS in prisons: 2002 Report Card

In 2002, over five years after the release of the 1996 Final Report, and 10 years after CSC created ECAP, it was time to assess whether the call for action made in the Final Report had been heard, and to document what progress, if any, had been made in Canada in responding to HIV/AIDS in prisons.

Some jurisdictions have totally and abysmally failed to wake up to the reality of HIV/AIDS, HCV, and injection drug use in prisons.

A questionnaire was developed and sent to the federal and provincial/territorial ministers of health and ministers responsible for corrections in September 2001, asking them what actions they had undertaken to respond to the recommendations in the 1996 Final Report. Follow-up interviews took place in September 2002 to verify and update the information provided. Responses were received from all 14 jurisdictions.

The 2002 Report Card summarizes the information provided and comments on it. It highlights positive action undertaken by prison systems since 1996, as well as presenting a detailed picture of the current state of HIV/AIDS programs and services in the prisons of each jurisdiction. An overview of significant national trends is also provided.

It is hoped that this information will assist each jurisdiction in assessing where they are, and where they should be, in responding to HIV/AIDS and HCV.

The following are some of the main findings.

Prevalence of HIV/AIDS and HCV

The prevalence of HIV/AIDS and HCV in federal and provincial prisons has continued to increase since 1996. In particular, in Canada’s federal prison system, the number of reported cases of HIV/AIDS rose from 14 in January 1989 to 159 in March 1996 and 217 in December 2000 (the last month for which statistics were available at the time the Report Card was written).⁸ This means that since the release of the 1996 Final Report, known cases of HIV/AIDS increased by over 35 percent within a four-year period.

Known cases of HIV infection among women in federal institutions were even higher, with 4.69 percent of incarcerated women known to be HIV-positive in December 2000. In one institution, Edmonton Institution for Women, 11.94 percent of prisoners were known to be HIV-positive.

The actual numbers may even be higher: the reported cases, provided by CSC, include only cases of HIV infection and AIDS known to CSC, but many inmates may not have disclosed their HIV status to CSC, or may not themselves know that they are HIV-positive.

Generally, about one in 600 (approximately 50,000 of 30 million) Canadians are living with HIV, but depending on the various studies undertaken, one in 100 to one in nine prisoners are living with HIV. This means that the proportion of prisoners with HIV is six to 70 times higher than the proportion of all

Canadians with HIV.

HCV prevalence rates in prisons are even higher than HIV prevalence

Basic HIV prevention measures continue to be denied to prisoners.

rates, and have continued to rise since 1996. Overall, 19.2 percent of all federal prisoners and 41.2 percent of women prisoners were known to be HCV-positive in December 2000. At Edmonton Institution for Women, 74.6 percent of prisoners were known to be HCV-positive. One in 125 (approximately 240,000 = 0.8 percent) Canadians are living with HCV, but one in five to more than one in two prisoners (20 to 80 percent) are living with HCV.

Governments’ response

There have been some significant, positive developments since the release of the 1996 Final Report. Some jurisdictions have implemented a number of the recommendations and have undertaken noteworthy, sometimes innovative, initiatives. No jurisdiction, however, has implemented all the recommendations, and some jurisdictions have totally and abysmally failed to wake up to the reality of HIV/AIDS, HCV, and injection drug use in prisons. Among the key findings:

- All Canadian governments are failing to provide the resources, leadership, and vision necessary to address, in a comprehensive and progressive fashion, the issues raised by HIV/AIDS, HCV, and injection drug use in prisons.

- There is a lack of coordination and harmonization of prison HIV/AIDS programs and services across the country. As a result, the standard of care available to prisoners varies widely between jurisdictions, and often between institutions within a given jurisdiction.
- Basic HIV prevention measures continue to be denied to prisoners.
- In a few jurisdictions, condoms, dental dams, and lubricant are still not available to prisoners. Even where they are available, they are often not accessible enough.
- Bleach remains unavailable in many jurisdictions.
- Needle exchange or distribution programs have yet to be piloted in Canadian prisons, although the steadily increasing number of prison syringe distribution programs in Western and Eastern Europe over the past 10 years provides conclusive evidence that such programs can be successfully implemented in prisons; and CSC's own committee, tasked with examining needle exchange programs, concluded in 1999 that they should be piloted in all regions of Canada.
- In most jurisdictions, methadone maintenance treatment has become available at least to those prisoners who were on such treatment before being incarcerated.
- Most jurisdictions have failed to embrace a harm-reduction approach to drug use.
- With some notable exceptions,

provision of HIV and HCV prevention education for prisoners is poor. Education is not mandatory in the vast majority of jurisdictions, and some correctional systems still do not provide basic HIV educational programs. In many jurisdictions, HIV training for prison health staff is rare or non-existent.

- Significant barriers still exist in most jurisdictions to the optimal use of HIV combination therapies.
- There are few HIV programs and services designed specifically for

“We must take all proper steps to protect prison officers and prisoners alike. By protecting them we protect society.”

incarcerated women.

- HIV programs for Aboriginal prisoners are also rare, and are unavailable even in some of the jurisdictions in which the majority of incarcerated people are Aboriginal.

Conclusion

Prison systems have a moral, but also a legal responsibility to act without further delay to prevent the spread of infectious diseases among prisoners, and to prison staff and the public, and to care for prisoners living with HIV and other infections. Canadian prison

systems continue to fail to meet this responsibility. Some positive developments have occurred since 1996, but Canadian governments are clearly not doing all they could.

Although they live behind prison walls, prisoners are still part of our communities and deserve the same level of care and protection provided to people on the outside. They are sentenced to be imprisoned, not to be infected.

Therefore, once again, the Report Card calls upon the federal and provincial/territorial governments to show more leadership, action, and commitment, and to implement all the recommendations in the 1996 Final Report.

As Justice Kirby of the High Court of Australia states, we owe it to the prisoners, and we owe it to the community, to protect people from infection while they are incarcerated. “This requires radical steps before it is too late.... The infection of a person who is in the custody of society, because that person does not have access to ready means of self-protection and because society has preferred to turn the other way, is ... unpalatable.... As a community we must take all proper steps to protect prison officers and prisoners alike. By protecting them we protect society.”

The 72-page Report Card, an info sheet summarizing its main findings, and the press release issued on 20 November 2002 are available on the Legal Network's website at www.aidslaw.ca/Maincontent/issues/prisons.htm.

Canada: Parliamentary Committee Makes Recommendations to Correctional Service Canada

As discussed in the preceding feature article in this issue, in December 2002 the House of Commons Special Committee on Non-Medical Use of Drugs released a report entitled *Policy for the New Millennium: Working Together to Redefine Canada's Drug Strategy*.⁹ The report contains a chapter on "substance use and public safety" with several recommendations on alternatives to prosecution and/or incarceration for people whose criminal behaviour is linked to drug dependence. In addition, the report examines the issues relating to drug use in federal correctional institutions. Without specifically mentioning needle exchange programs, the Committee recommends that prisoners have access to such programs "in a manner consistent with the security requirements within institutions."¹⁰

The relevant recommendation reads as follows: "The Committee recommends that Correctional Service Canada [CSC] allow incarcerated offenders access to harm-reducing interventions, in order to reduce the incidence of blood-borne diseases, in a manner consistent with the security requirements within institutions."¹¹ In their "supplementary report from the official opposition," Canadian Alliance MPs Randy White and Kevin Sorenson call this recommendation "preposterous," saying that "[w]e cannot permit inmates to have access to needles, through needle exchanges simply because it is dangerous for guards and for other inmates as well." Here, as throughout their supplementary report, White and Sorenson display a lack of knowledge and understanding that seems shocking for people who had the benefit of participating in an 18-month process of intense study of drugs and drug use. The Committee was presented with evidence from many European prisons where needle exchange programs have existed for up to ten years, and where prison staff themselves have expressed that, far from being a security risk, needle exchange programs have actually contributed to safety and security in prisons. Experts in Canada and

internationally have recommended that needle exchange programs be introduced in prisons, in light of the significant benefits demonstrated in the evaluations of existing prison needle exchange programs.¹²

Other recommendations relevant to CSC include:¹³

- that CSC be required to develop and implement a three-year plan to reduce substantially the flow of illicit drugs into prisons;
- that CSC provide prisoners with access to substitution therapies, such as methadone, based on eligibility criteria similar to those used in the community at large;
- that CSC "continue to promote abstinence as its overriding treatment objective";
- that CSC undertake, as a pilot project, the establishment of two federal correctional facilities reserved for offenders who wish to serve their sentence in a substance-free environment with access to intensive treatment and support; and
- that CSC ensure that there are sufficient programs and spaces available to allow offenders access to treatment for substance use, as needed, immediately following their incarceration.

In her supplementary report, NDP MP Libby Davies questions the viability of the recommendations that promote abstinence as CSC's overriding treatment objective and that mandate CSC to develop and implement a three-year plan to reduce substantially the flow of illicit drugs into prisons. According to her, these recommendations

fail to deal with the reality of drugs in our prisons. The NDP would place greater emphasis on adopting harm reducing measures, such as needle exchanges and widespread access to treatment, as a more practical solution.

Davies continues by saying that "the NDP believes that recommendation 34 (establishment of two drug-free facilities for offenders) is contradictory, counter-productive and discriminatory to the need for adequate treatment services being made available to all offenders, as outlined in recommendation 35."

In fact, the Committee's analysis of the situation with regard to drug use in prisons is at best incomplete and is based on a poor understanding of what is happening behind the bars of federal correctional institutions with regard to drug use, treatment, prevention, and interdiction efforts. CSC has already vastly increased the resources it devotes to efforts to prevent drugs from coming into the institutions. Among many other things, so-called "intensive support units" (or drug-free units) have been opened in nearly all federal institutions. As is the case outside prisons, it is crucial that more resources be devoted to treatment, prevention, and harm-reduction efforts, rather than to failing supply-reduction strategies, despite the wealth of scientific evidence demonstrating their ineffectiveness.¹⁴

Ireland: Report Calls for Action on HIV and HCV in Irish Prisons

HIV and hepatitis C infection have reached epidemic levels in Irish prisons, yet the Irish Prisons Service's provision of HIV and HCV prevention measures and health services falls far short of those available in the community, and of best-practice models in other European and North American jurisdictions. These are among the key findings of a report released in Dublin in July 2002. *A Call for Action: HIV and Hepatitis C in Irish Prisons* was published jointly by the Irish Penal Reform Trust and Merchants Quay Ireland.¹⁵ Based on Irish and international research and experience, the report provides 21 recommendations to the Irish government for implementing a comprehensive and compassionate response to HIV and HCV in the prisons.¹⁶ The report is summarized here by its author, Rick Lines. For further information, Rick can be reached at ricklines@yahoo.com.

Current situation

HIV infection rates among incarcerated people in Ireland are more than 10 times higher than in the outside population. Rates of HCV infection are more than 100 times higher.¹⁷ Studies have repeatedly shown that high-risk behaviours for the transmission of HIV and HCV – such as the sharing of injection equipment, unprotected sexual intercourse, and tattooing – not only occur in Irish prisons, but are common.¹⁸

While the mandate of the Irish Prison Medical Service is “to provide primary health care (prevention, treatment and health rehabilitation) to offenders of at least an equivalent standard to that available to citizens in the general community,”¹⁹ the report concludes that the response of the Prisons Service lags far behind international best practice in almost every major area. Harm-reduction measures such as bleach and syringe exchange are not available to prisoners. Ireland remains one of the only jurisdictions in the European Union that does not provide condoms for prisoners. Methadone is available only in prisons in the Dublin area, and then primarily to those on the therapy at the time of incarceration.²⁰

The report also finds that access to health-care services is inconsistent and inadequate for prisoners living with HIV/AIDS and/or HCV. Primary health-care services are provided by general practitioners contracted on a part-time basis only, and many nursing services are not provided by trained nurses but by medical orderlies – prison guards with only basic first-aid training. The report notes that there are currently no “hospital” facilities within Irish prisons, and that while a “medical unit” does exist in Mountjoy Prison in Dublin, it was recently described as “unsuitable for most medical purposes.”²¹ Many prisoners living with HIV/AIDS are housed in this unit.

Recommendations

The report makes recommendations in three areas.

In the area of *Prevention and Education*, the report calls on the Irish government to make available in prisons the same prevention and harm-reduction measures that have been proven effective in the community. Access to condoms, full-strength bleach, and syringe exchange programs must be implemented as a mat-

ter of urgency. The Prison Service's methadone program must be expanded to prisons outside the Dublin region.

In the area of *Care, Treatment, and Support*, it recommends that adequately staffed and resourced health units be developed in all institutions. Access to comprehensive medical services must be made consistent across the state and between institutions. Prisoners living with HIV/AIDS and/or HCV must have access to proper and sufficient nutrition, and must be provided equal and non-discriminatory access to drug therapies and pain-management medications.

In the area of *Confidentiality and Testing*, it recommends that confidential HIV and HCV testing be made easily accessible for all prisoners, and that pre- and post-test counselling be made a mandatory component of testing protocol.

Reaction

The report was released at a public launch in Dublin on 26 July 2002. Community-based organizations have widely welcomed the report, and it is hoped that the findings will provide a basis for future advocacy. The report and its recommendations received extensive media attention, and were covered by the major print, television, and radio outlets.²² The *Irish Examiner*, a major daily newspaper, ran an editorial calling on the government to implement the report's recommendations.

Response from the Prison Officers' Association, the union representing prison guards, was less enthusiastic. Their spokesperson spoke out against the introduction of needle exchange programs in prisons, although they did

demonstrate willingness to consider condom distribution.²³

At the time of writing, the Minister of Justice had yet to formally respond to the report.

Electronic copies of *A Call for Action: HIV and Hepatitis C in Irish Prisons* by Rick Lines (Irish Penal Reform Trust/Merchants Quay Ireland: July 2002) may be obtained from the author at ricklines@yahoo.com. Hard copies may be obtained from either the Irish Penal Reform Trust or Merchants Quay Ireland through the websites listed in end-note 15.

Other Developments

This note provides a summary of other noteworthy events, developments, or publications in the area of HIV/AIDS, HCV, and drug use in prisons.

Bleach better than nothing

A new study suggests that bleach may help curb the spread of HCV. Writing in *Epidemiology* in November 2002, Kapadia and Vlahov, researchers with the New York Academy of Medicine, reported that among more than 450 drug users studied, those who said they cleaned their needles with bleach all the time were 65 percent as likely to be infected with HCV than those who did not use bleach at all. Those who said they used bleach “less than all the time” had a 24 percent lower risk.

The authors emphasized that the surest ways to avoid infection were abstaining or using sterile needles. However, for others, using bleach to clean their syringes offers an option to reduce the risk of HCV transmission. “Bleach is better than doing nothing,” Vlahov said, “but it is not a substitute for clean needles each and every time.”²⁴

Russia: 36,000 prisoners with HIV/AIDS

According to a report that quoted Russian Deputy Justice Minister Yuri Kalinin, “the most acute problem among prisoners is the growing number of prisoners with AIDS.” He said that about 36,000 of 891,000 people currently in jail in Russia live with

HIV or AIDS. 90,000 prisoners suffer from TB, and up to 300,000 have mental health problems.²⁵

Italy: One in 10 Italian prisoners HIV-positive

An alarming number of Italian prisoners are infected with HIV, according to preliminary data presented on 26 November 2002 in Turin, Italy. The estimate is based on a study undertaken in 14 of Italy’s 217 prisons.

According to Dr Starnini, president of the Italian society of penitentiary health and medicine, between 5000 and 7000 prisoners in Italy could be HIV-positive. Most prisoners who tested positive in the study did not know they were HIV-positive. The full results of the survey, together with more discussion on the health situation in Italian prisons, will be presented in May 2003.²⁶

Lithuania: Prison outbreak of HIV frightens nation

During random checks undertaken in 2002 by the state-run AIDS Center, 263 prisoners at Alytus prison in Lithuania tested positive for HIV. Tests at Lithuania’s other 14 prisons found only 18 cases. Before the tests at Alytus prison, Lithuanian officials had listed just 300 cases of HIV in the whole country, or less than 0.01 per-

cent of the population, the lowest rate in Europe. It has been said that the outbreak at Alytus is due to sharing of drug injection equipment. Complaining about the conditions in the prison, one prisoner said: “Pigs would not eat what we eat. There’s no work to be done. Drugs are the only entertainment.”²⁷

New Zealand: Condoms and needles?

According to a newspaper article, in 2002 the New Zealand Corrections Department and Health Ministry recommended that harm-reduction programs, including condoms and clean needles, be introduced in prisons. However, as of September 2002, there was no official policy on condoms or clean needles.²⁸

Malawi: HIV/AIDS project reaches out to prisoners

The Health in Prisons project is being implemented in 21 prisons across Malawi. Apart from disseminating information and education materials on the prevention of HIV, the program provides free treatment for STIs, malaria, and scabies. Prisoners are also informed of various family planning services in clinics, to encourage them to access family planning services when out of prison. But the project

has been advocating for condom distribution in prisons to no avail. Prison authorities “refuse to accept” that unsafe sexual activity in prisons occurs. A person responsible for the project noted: “In our experience, there is so much high-risk behaviour taking place. We get a lot of cases of genital ulcers and other STIs that indicate this.”²⁹

Zambia: Robust response needed in prisons

In a letter to the editor of the *British Medical Journal*, Simooya and Sanjobo reported on a survey of HIV seroprevalence and risk behaviours in Zambian prisons. Prevalence of HIV was 27 percent compared to a national average of 19 percent. The authors said that “some inmates may be getting infected inside prison. Only 4% of inmates agreed in one to one interviews that they had sexual relations with other men, but indirect questioning suggested that the true figures were much larger. No condoms were available in any prison.” 17 percent of prisoners had been tattooed in prison, and 63 percent reported sharing razor blades.³⁰

Resources/Publications

Consensus statement calls for expanding HCV treatments

Most of the prison systems in the US are likely to revise their treatment approaches and protocols for HCV to reflect a consensus statement released in September 2002 that calls for expanding HCV treatments to populations formerly excluded from treatment. In September, a 12-member panel convened by the US National Institutes of Health (NIH) issued a final HCV consensus statement saying that injection drug users, people who consume alcohol, and

others suffering from co-morbid conditions such as depression and HIV should be considered for treatment.³¹ The new consensus statement represents a major departure from the last consensus statement issued by a similar NIH-convened panel in 1997 that excluded these groups from treatment. The US Federal Bureau of Prisons is rewriting its HCV treatment guidelines to reflect the new consensus statement. Many state prison systems are likely to follow the example, implementing protocols that eliminate former barriers to treatment.

www.hcvinprison.org

The website of the (US) National Hepatitis C Prison Coalition, which includes a collection of HCV treatment guidelines for 20 state correctional departments.

2000 US HIV in prisons report

The Bureau of Justice Statistics year 2000 US HIV in prisons report became available online in November 2002.³² This annual report provides the number of HIV-positive and active AIDS cases among prisoners held in each state and the US federal prison system at year-end 2000. The report provides prison data on the number of AIDS-related deaths, HIV testing policies, a breakdown for women and men with AIDS, and comparisons with AIDS rates in the general population.

A review of the legal and ethical issues for the conduct of HIV-related research in prisons³³

This article describes barriers to access to clinical trials, the demographics of HIV/AIDS in prisons in the US, the unique situation posed by the potential for HIV-related research in prisons, and examines the history

of prisoner research in the US. It considers both ethical and legal responses to clinical trials in prisons, makes recommendations for conditions necessary to conduct ethical research in prisons, and calls for more cooperation between prison systems and HIV/AIDS clinical trials researchers to make expanded access to clinical trials a reality.

¹ Lines R. *Action on HIV/AIDS in Prisons: Too Little, Too Late – A Report Card*. Montréal: Canadian HIV/AIDS Legal Network, 2002 (available via www.aidslaw.ca/Maincontent/issues/prisons.htm).

² See Jürgens R. *HIV/AIDS in Prisons: Final Report*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, September 1996, at 5, for a listing of organizations that have addressed the issue of HIV/AIDS in prisons between 1987 and 1992. The Final Report is available via www.aidslaw.ca/Maincontent/issues/prisons.htm.

³ See, in particular, World Health Organization. *Statement from the Consultation on Prevention and Control of AIDS in Prison. Global Programme on AIDS*. Geneva: WHO, 1987; and the WHO *Guidelines on HIV Infection and AIDS in Prisons*. Geneva: WHO, 1993. Available as appendix 5 of the 1996 Final Report, supra, note 2.

⁴ PASAN. *HIV/AIDS in Prison Systems: A Comprehensive Strategy*. Toronto: PASAN, June 1992.

⁵ Correctional Service Canada. *HIV/AIDS in Prisons: Final Report of the Expert Committee on AIDS and Prisons*. Ottawa: Ministry of Supply and Services Canada, 1994.

⁶ Supra, note 1.

⁷ Ibid at 98.

⁸ Correctional Service of Canada. *Infectious Diseases Year 2000*. Ottawa: CSC, 13 February 2001. All data about HIV/AIDS and HCV in federal prisons are from this document.

⁹ House of Commons Canada. *Policy for the New Millennium: Working Together to Redefine Canada's Drug Strategy*. Report of the Special Committee on Non-Medical Use of Drugs. Ottawa: House of Commons, December 2002. Available at www.parl.gc.ca/InfoComDoc/37/2/SNUD/Studies/Reports/snudrp02-e.htm.

¹⁰ Ibid at 106.

¹¹ Ibid (recommendation 32).

¹² See many articles on this subject in the *Canadian HIV/AIDS Policy & Law Review* (available via www.aidslaw.ca/Maincontent/otherdocs/Newsletter/newsletter-toc.htm#p).

¹³ Supra, note 9, recommendations 30-31 and 33-35.

¹⁴ Wood E et al. Impact of supply-side policies for control of illicit drugs in the face of the AIDS and overdose epidemics: investigation of a massive heroin seizure. *Canadian Medical Association Journal* 2003; 168(2): 165-169 at 168, with many references.

¹⁵ The Irish Penal Reform Trust is the main prisoners' rights organization in Ireland (www.penal-reform.ie). Merchants Quay Ireland is one of Ireland's oldest AIDS

service organizations and one of the state's primary advocates for the rights of drug users and providers of harm-reduction services (www.mqj.ie).

¹⁶ This report refers to the prisons located in the 26 counties of the Republic of Ireland. It does not address those in the 6 counties in Northern Ireland.

¹⁷ A 1999 study of 1200 incarcerated men and women found an overall HIV infection rate of two percent and an HCV infection rate of 37 percent. The same study found that nearly half the incarcerated women tested were infected with HCV. See Allwright S et al. *Hepatitis B, Hepatitis C and HIV in Irish Prisoners: Prevalence and Risk*. Dublin: The Stationary Office, 1999. A 2000 study of 600 remand prisoners found an overall HIV infection rate of two percent and HCV infection rate of nearly 22 percent. Among women prisoners, the HIV seroprevalence rate was nearly 10 percent, and the HCV infection rate was 56 percent. See Long J et al. *Hepatitis B, Hepatitis C and HIV in Irish Prisoners, Part II: Prevalence and risk in committal prisoners 1999*. Dublin: The Stationary Office, 2000. For more details on these reports, see HIV/AIDS in prisons: new developments. *Canadian HIV/AIDS Policy & Law Review* 2002; 6(3): 13-19 at 17-18 (available via www.aidslaw.ca/Maincontent/otherdocs/Newsletter/newsletter-toc.htm#p).

¹⁸ Ibid.

¹⁹ Department of Justice. *The Management of Offenders – A Five Year Plan*. Dublin: The Stationary Office, 1994, at 51.

²⁰ For more information on methadone access in Irish prisons, see R Lines. Irish prison guards call for expansion of methadone access. *Canadian HIV/AIDS Policy & Law Review* 2001; 6(1/2): 71-74.

²¹ Group to Review the Structure and Organisation of Prison Health Care Services. *Report of the Group to Review the Structure and Organisation of Prison Health Care Services*. Ministry of Justice, Equality and Law Reform, Dublin: The Stationary Office, September 2001, at 43. Available online at www.irishprisons.ie.

²² For example, see www.rte.ie/news2/2002/0726/prison.html.

²³ Ibid.

²⁴ Nagourney E. Prevention: new ideas on bleach and needles. *New York Times* 19 November 2002.

²⁵ More than half of Russian convicts are ill. 27 November 2002 (ITAR-Tass and Interfax news agencies).

²⁶ Lorenzi R. One in 10 Italian prisoners HIV positive: study. Reported by *Health – Reuters*, 27 November 2002.

²⁷ Dapkus L. Prison's rate of HIV frightens a nation. *Associated Press* 29 September 2002.

²⁸ Scanlon G. Prisoners get condoms and needle cleaner. *Dominion Post* (Wellington, New Zealand), 23 September 2002.

²⁹ Malawi: HIV/AIDS project reaches out to prisoners. *PlusNews* 13 November 2002.

³⁰ Simooya O, Sanjobo N. Study in Zambia showed that robust response is needed in prisons. *British Medical Journal* 2002; 324(6 April): 850.

³¹ The final consensus statement can be accessed via http://consensus.nih.gov/cons/116/116cdc_intro.htm.

³² www.ojp.usdoj.gov/bjs/abstract/hivp00.htm

³³ Lazzarini Z, Altice FL. *AIDS & Public Policy Journal* 2000; 15(3/4): 105-135.

The 1st Annual Awards for Action on HIV/AIDS and Human Rights

cont'd from page 1

Vancouver Area Network of Drug Users (VANDU)

With over 1000 members and 800 peer volunteers, VANDU has been recognized as one of the strongest user organizations in the world. It originated and continues to work in the Downtown Eastside of Vancouver. The neighbourhood is among the most impoverished in Canada, and many of its residents contend with enormous risks to health. From 1996 to 2000 there was an average of 300 overdose deaths a year, making drug-related overdose the leading cause of death among adults between the ages of 30 and 49. In 1997 an explosive HIV epidemic that remains among the highest ever observed in the developed world was documented among the neighbourhood's drug users. As well, over 90 percent of drug users in

the neighbourhood are living with hepatitis C.

With over 1000 members and 800 peer volunteers, VANDU has been recognized as one of the strongest user organizations in the world.

In 1997 a group of individuals gathered to form a user-run organization, which eventually became VANDU. The founders felt that little had been done in response to the health emergency and that the voice of users had not been heard. VANDU's earliest work involved setting up discussion groups. The first

group took place in the heart of the open drug scene in Oppenheimer Park. The organizers asked users to voice their concerns and needs. The first questions were simple and included: "What are the issues facing drug users?" and "What would most help you now?" Facilitators then documented the concerns raised. The organizers continued to place notices about the meetings throughout the neighbourhood, and within a couple of months hundreds of users were attending meetings to plan user-based actions.

Over time, VANDU has increased its capacity and expanded its activities. In addition to ongoing political activism and participation on community and government task forces, VANDU is engaged in public education and in providing care and support programs for drug users. Current

activities include support groups for women with HIV, persons with hepatitis C, and methadone users, as well as a syringe exchange and recovery program, alley patrols, and street-, hotel-, and hospital-based support programs.

One example of the innovative work of VANDU is its alley-patrol program. VANDU recognized that there was a huge increase in the number of fatal overdoses following the day that social assistance cheques are issued (known as Welfare Wednesday). It ensured that volunteers obtained cardiopulmonary resuscitation and first-aid training and began patrolling the alleys and other locations where very few health-care workers would dare venture. They went out in shifts, 24 hours a day, for three days straight. They provided first aid and syringe exchange, and responded to overdoses and other emergencies.

Because many users experienced difficulty accessing clean syringes after the fixed needle exchange closed at 8 pm each night, VANDU decided to open a syringe exchange table at the corner of Main and Hastings. It is run by two shifts of volunteers between the hours of 8 pm and 4 am, and approximately 1200 rigs are exchanged each night. Despite the fact that difficulty accessing syringes is the most robust predictor of HIV infection in the Downtown Eastside, the police recently shut down the VANDU table. It was re-opened after lobbying by health researchers and activists (see the article in Canadian News in this issue: Vancouver Police Raid Needle Exchange Run by Drug Users).

VANDU has also affected the culture of drug use in the Downtown Eastside by fostering a sense of mutual caring and responsibility among

people who use drugs. They have done this by promoting peer support, safer drug use, and participation in the local community. The impact of participation in VANDU should not be underestimated. A founding member of VANDU described it as follows:

It brings together a collective experience and wisdom, but also you begin to get a different feeling about yourself. To become part of something for who I am and not for who I am not. For who I am is an addict. I'm poor, I've got hep C, I live in wretched housing and all this, and then someone says, "Yeah, that all makes you a really valuable person. You have a lot to contribute to try to help people and to save other lives, and your experience can do that." Then I get a different feeling about myself.²

Dean Wilson, a member of VANDU's Board, and Ann Livingston, a Project Coordinator, accepted the award on behalf of VANDU. Mr Wilson asked for a moment of silence to remember the 3000 people whose lives have been lost in the Downtown Eastside. Ms Livingston said:

I wish we had more reason to celebrate. I wish that we could say that we have safe injection sites, and that the number of deaths has been reduced to a more reasonable number, whatever that is. We don't step back often in VANDU to see what we have accomplished. It is a very embattled kind of atmosphere in the Downtown Eastside because it runs day and night, and for the most part we just live it. It is not really a job, it is more of a calling.

I have to admit that we are tired of waiting for the recommendations from the many reports that have been issued to become

"I wish that we could say that we have safe injection sites, and that the number of deaths has been reduced to a more reasonable number, whatever that is."

— Anne Livingston³

actions. What VANDU and all drug users need is for "straight" people with reputations, with education and with some social status to stand with the poorest of the poor and say, "It's not okay to just let these people die."⁴

Dr Wan Yanhai

Dr Wan Yanhai is coordinator of the AIZHI (AIDS) Action Project, a non-governmental organization he founded in 1994. Based in Beijing, the project provides some of the only information on HIV/AIDS available to people in China through a widely used website (www.aizhi.org).

Dr Wan graduated from Shanghai's Fudan University School of Medicine in 1988, and was on the staff of the National Health Education Institute from 1988 to 1994. During that time he was instrumental in setting up the first government programs to provide counselling and information about HIV transmission and AIDS. Dr Wan helped to set up and run China's first AIDS telephone hotline. The initial focus of the hotline was to provide general information about HIV/AIDS and preventing HIV transmission. Under Dr Wan's direction, the hotline also became a vehicle to promote gay rights.

Health authorities had argued that the spread of HIV in China could be controlled by preventing people with

HIV from entering the country and by isolating them within China. This official line conflicted with Dr Wan's view that HIV/AIDS should be approached as an issue of political and civil rights. While the government was reluctant to accept that the gay community was at risk, Dr Wan argued that homosexuals should be allowed to form support groups to help combat the spread of the virus. He also publicly advocated for the formation of self-help groups for sex workers and intravenous drug users.

After he began speaking out about the rights of gays and other marginalized groups, Dr Wan was accused of promoting homosexuality and prostitution. In 1993 the government's HIV/AIDS counselling program was terminated. A year later Dr Wan was dismissed from his job.

Since the mid-1990s, Dr Wan has coordinated the AIZHI Action Project (a network of activists) to tackle massive ignorance about HIV/AIDS and to expand prevention efforts in China. Through education, counselling, opinion polls, research, publishing, and conferences aimed at drawing up policy recommendations for the government, the AIZHI Action Project provided the first glimpses into China's gay population and its health needs.

Recently the AIZHI Action Project has expanded its HIV/AIDS education and assistance programs to include sex workers and rural or migrant workers. Dr Wan and his colleagues are also coordinating efforts to assist hundreds of orphans whose parents have died of AIDS. Facing enormous social discrimination, China's AIDS orphans have been left with little government assistance and many have been forced out of school due to ignorance about how HIV is transmitted.

The blood collection scandal in Henan Province

Under Dr Wan's leadership, the group has coordinated a remarkable campaign in Henan province, where hundreds of thousands of rural villagers have contracted HIV through unsanitary blood-collection practices

Dr Wan "has taken extraordinary risks to break down the conspiracy of silence around AIDS in China and protect the rights of those infected."

— Ralf Jürgens⁵

conducted at government health facilities. People sold their blood to the biological products industry in order to supplement their income. The desired commercial product was plasma. After it was extracted, the blood from communities of sellers was pooled and re-injected into their arms. HIV-infected blood from one individual could thus infect the entire pool.

Dr Wan and his colleagues have worked to overcome government regulations, attempts by local authorities to cover up the rural HIV/AIDS epidemic, and widespread social prejudice against victims of the blood-collection scandal and their families. In the face of ongoing police harassment and threats from government officials, AIZHI activists continue to visit villages in Henan, documenting the extent of HIV infection and developing recommendations for social action and government assistance. As part of these efforts, Dr Wan's group has organized youth volunteers in Beijing to

join the Henan campaign, working in partnership with youth in targeted villages to distribute basic information and educational materials on HIV/AIDS.

Dr Wan detained by the government

Despite the crucial role it has come to play in addressing HIV/AIDS in China, the AIZHI Action Project continues to face considerable difficulties. In July 2002, the organization was evicted from its offices at a private university in Beijing after the university was pressured by government officials to shut the organization down. The action came four days after a report from the United Nations criticized the government for inaction in the face of a raging AIDS epidemic, and some weeks after Dr Wan's organization publicized details about the deaths of 170 persons in Henan province from HIV/AIDS contracted through blood collection.

On 24 August 2002, Dr Wan was detained by the Ministry of State Security. For several weeks his wife, Su Zhaosheng, who is studying in the United States, did not know where he was. It was later confirmed that he was detained for forwarding to an electronic mailing list a classified health document concerning the AIDS epidemic among people who sold blood in Henan province. Su Zhaosheng accepted the International Award for Action on HIV/AIDS and Human Rights in Montréal on her husband's behalf. (The decision to present the award to Dr Wan was not related to his detention. It was made in July by an International Advisory Committee at the XIV International AIDS Conference in Barcelona.)

In September there was an international outcry about Dr Wan's imprisonment, including demonstra-

tions in New York and Paris. Officials at the State Department in the United States expressed concern about his disappearance in view of President Jiang Zemin's impending visit to that country, and Chinese health authorities were warned that their application for US\$90 million from the Global Fund for AIDS, Tuberculosis and Malaria would not be approved as long as Dr Wan was detained.

Dr Wan was released on 20 September 2002. While in prison he was unaware of the international campaign for his release. "I'm extremely moved and grateful," he said. "I was also extremely moved that all my friends here involved in

fighting AIDS did not back down or give up because of my case." Dr Wan vowed that his work against AIDS in China would not be hindered. He said, "If this incident helps attract more concern and support for victims of AIDS and their families and children here in China, then it can be considered an opportunity we should grasp."⁶

– *Thomas Kerr and Thomas Haig*

Thomas Kerr is a research coordinator at the British Columbia Centre for Excellence in HIV/AIDS. He can be reached at thkerr@shaw.ca. Thomas Haig is the Communications Coordinator of the Canadian HIV/AIDS Legal Network. He can be reached at thaig@aidslaw.ca.

¹ For information about the awards and the first recipients, see 1st Annual Awards for Action on HIV/AIDS and Human Rights. Montréal: Canadian HIV/AIDS Legal Network and Human Rights Watch, 2002 (www.aidslaw.ca/Maincontent/awards/e-brochure2002.pdf). For a transcript of remarks made at the presentation of the awards, see Ten Years of Action for Health and Human Rights: Presentations Made on the Occasion of the Canadian HIV/AIDS Legal Network Annual General Meeting and Skills Building Workshop. Montréal: Canadian HIV/AIDS Legal Network, 2002 (www.aidslaw.ca/Maincontent/events/agm2002/proceedings.pdf).

² 1st Annual Awards, *supra*, note 1 at 6.

³ Ten Years of Action, *supra*, note 1 at 26.

⁴ *Ibid.*

⁵ Canadian HIV/AIDS Legal Network and Human Rights Watch. Chinese AIDS activist honoured despite ongoing detention. Press release. 12 September 2002.

⁶ China frees AIDS activist after month of outcry. *New York Times*, 21 September 2002.

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 obtained through 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.

Canada Refuses to Issue a Visa to an HIV-Positive Worker on Antiretroviral Drugs

Citizenship and Immigration Canada has denied an application for a visa from an HIV-positive man even though he is in good health. The man was seeking to fill a two-year work term in Canada. The case raises concerns about Canada's immigration policies for people with HIV and about the ability of organizations working in AIDS to hire HIV-positive foreign workers.

Citizenship and Immigration Canada (CIC) has turned down an application from an HIV-positive man for a visa to enable him to take up a two-year position at an international HIV/AIDS organization. The CIC ruled that Shaun Mellors was medically inadmissible. Mr Mellors did receive a temporary residence permit instead, but the permit comes with a code that means he is unlikely to receive provincial medical insurance while in

Canada. Mr Mellors will have to pay for any medical care, including emergency care, whether or not the condition is related to his HIV diagnosis.

Under Canada's immigration law,¹ foreigners can be refused entry into Canada based on their medical condition if it is expected that they will place excessive demand on government services. Demand is considered excessive if the financial burden a person would place on government serv-

ices each year is greater than that of the average Canadian. The burden is calculated over a five-year period, which can be extended to ten years for chronic diseases.² The contributions an individual is expected to make, whether economic or social, are not taken into account. Refugees, sponsored spouses, common-law partners, and children of Canadian citizens are exempt from the excessive-demand clause.

Mr Mellors, who is from South Africa and is open about his HIV status, was hired by the International Council of AIDS Service Organizations (ICASO) to fill a vacancy in its Toronto office in the position of Vaccine Policy Coordinator. The position requires an individual with experience in community preparedness for HIV vaccine trials in developing countries. ICASO received approval from Human Resources Development

Canada to hire Mr Mellors due to the lack of qualified candidates in Canada.

The medical tests conducted on Mr Mellors revealed that he is in good health. He is currently taking antiretroviral medication, but has never had an HIV-related illness. In response to enquiries from organizations concerned about Canada's immigration policies respecting people with HIV/AIDS, the CIC has revealed that any applicant for a work visa or permanent residence who is HIV-positive and is on antiretroviral medication will be declared medically inadmissible unless that person has private medical insurance that covers the cost of the medication. The CIC's rationale is that the cost of the antiretroviral medication, which in the absence of private insurance is subsidized by provincial governments, constitutes excessive demand. The CIC says that a person with HIV/AIDS who is in good health and is not taking antiretroviral medication would not normally be considered medically inadmissible.

ICASO says that the decision means that it cannot hire foreign workers who are HIV-positive and who are on antiretroviral medication. As a non-profit organization, ICASO

does not have the means to pay for the cost of the drugs. It says that this harms ICASO's credibility as a leading non-governmental organization in global HIV policy and program-

Numerous reports in Canada have called for the implementation or a trial of safe injection facilities.

ming, and also harms Canada's reputation for fairness and for a balanced response to AIDS. ICASO and others are also concerned about the impact this decision will have on the International AIDS Conference that Toronto is scheduled to host in 2006. A conference secretariat will be established in Toronto and will need to be able to hire foreign workers who are HIV-positive.

By way of comparison, the International HIV/AIDS Alliance, an international organization based in the United Kingdom, has been able to hire to foreign workers with HIV/AIDS who are then covered by that country's National Health Service.

ICASO has raised this case and its broader implications with individuals in the offices of the Minister of Citizenship and Immigration, the Minister of Health, the Minister of Foreign Affairs and International Trade, and the Minister of International Cooperation, who have shown an openness to explore the issues it raises. Future developments are expected.

Visitors who plan to stay in Canada for six months or less do not usually have to take a medical exam. Since 15 January 2001, HIV testing has been performed on all other applicants who are 15 years of age or older (as part of the medical exam). When the medical tests were performed on Mr Mellors and his partner, no pre- or post-test counselling was provided, and the consent forms they were asked to sign were not explained to them.

— David Garmaise

¹ The *Immigration and Refugee Protection Act* became law on 28 June 2002. The text is available via the CIC website at www.cic.gc.ca.

² "Excessive demand" is defined in the *Immigration and Refugee Protection Regulations*, subsection 1(1), *Canada Gazette, Part II*, vol 136, 14 June 2002 (available via www.cic.gc.ca).

Supervised Injection Sites: Minister of Health Ready to Review Applications for Pilot Research Projects

Since 1 January 2003, Health Canada has been prepared to receive proposals for pilot supervised injection sites (SISs). Vancouver has already indicated that it will submit a proposal within a few months. Other cities that have expressed an interest in opening SISs include Montréal, Québec, Winnipeg, and Victoria.

Background

In the face of an ongoing and escalating health crisis among people who inject drugs in Canada, calls have come from many quarters to open SISs as a way to reduce overdose, the spread of bloodborne diseases, and other health and community problems associated with injection drug use.

In April 2002, the Canadian HIV/AIDS Legal Network released a

report analyzing the legal and ethical issues related to the establishment of SISs.¹ Among other things, the report recommended that “[t]he federal government ... create a regulatory framework under the *Controlled Drugs and Substances Act* (CDSA) to govern safe injection facilities that would eliminate the risk of criminal liability for staff and clients and reduce the risk of civil liability for operating such facilities.”² In the interim, before such a regulatory framework is in place, the report further recommended that “the federal Minister of Health should grant ministerial exemptions from the application of the provisions of the CDSA that make it an offence to possess a controlled substance to designated safe injection facilities (and needle exchange programs), and to their staff and clients, so that such facilities can open on a trial basis.”³

In October 2002, Minister of Health Anne McLellan indicated that Health Canada would be prepared to grant such ministerial exemptions and receive proposals for SISs beginning in January 2003. Subsequently, on 16 and 17 December 2002, Health Canada co-hosted a meeting on SISs with the Canadian Centre on Substance Abuse. At the meeting, a “Draft Interim Guidance Document for an Application for an Exemption Under Section 56 of the *Controlled Drugs and Substances Act* for a Scientific Purpose for a Pilot Supervised Injection Site Research Project” was discussed with participants: representatives of several Canadian municipalities (Montréal, Québec, Vancouver, Victoria, and Winnipeg), staff from Health Canada, one staff member each from Justice Canada and the Solicitor General Canada, and representatives of the Canadian HIV/AIDS Legal

Network, the Canadian AIDS Society, and the Canadian Association of Chiefs of Police.

The comments and recommendations made by the participants were taken into consideration in the preparation of a revised Draft Interim Guidance Document, distributed to meeting participants on 2 January 2003.⁴ In the note that accompanied the document, Health Canada stated that the document would be the basis for reviewing applications for pilot supervised injection site research projects as of 1 January 2003. Health Canada considers the document as a “living document” and anticipates making changes “as we gain further experience with the research information and the practicalities of the situation when pilot supervised injection site research projects are operating.”⁵

How to Apply: The Interim Guidance Document

The stated purpose of the document is “to provide guidance to applicants who wish to obtain an exemption under section 56 of the *Controlled Drugs and Substances Act* (CDSA) for a scientific purpose for a pilot Supervised Injection Site (SIS) research project in Canada.”⁶

The document briefly reviews the background of HIV/AIDS, hepatitis C, and injection drug use in Canada. It points out that “injection drug use is a serious health and social issue” and that the establishment of pilot SISs was suggested as a potential strategy in the 2001 report of the Federal/Provincial/Territorial (F/P/T) Committee on Injection Drug Use, *Reducing the Harm Associated with Injection Drug Use in Canada*.⁷ As a result, in February 2001, the F/P/T Committee established a multise-

toral Task Force on Supervised Injection Sites [the SIS Task Force] to examine the feasibility of establishing a scientific, medical research project regarding SISs in Canada. The SIS Task Force produced a *Consensus Statement on Supervised Injection Sites and Minimum Criteria for SIS Pilot Projects*, concluding that “a scientific, medical research project is feasible in Canada only if the following criteria are met:

1. The project has clear, measurable objectives and can be evaluated as a scientific, medical research project;
2. There is political support for the project at the national, provincial, and municipal levels;
3. An appropriate legal framework is put in place; and,
4. There is local support at the chosen site(s).⁸

The document then briefly reviews legal issues, rightly concluding that, without government intervention, clients of SISs would remain very much exposed to criminal charges of possession of illegal drugs. (The document also states that “[b]ecause there are no regulations applicable to SISs, the operation of a SIS would be considered illegal under the CDSA.”⁹ This statement is probably wrong as a matter of law. In reality, staff/operators of a SIS face relatively little risk of criminal liability.¹⁰) Therefore, the document continues, Health Canada will use section 56 of the CDSA “to enable the conduct of the pilot scientific, medical research projects recommended to evaluate SISs as a means to reduce the harm associated with injection drug use.”¹¹ Section 56 of the CDSA gives “the Minister the authority to exempt, on such terms and conditions as the Minister deems necessary, persons

from the application of all or some of the provisions of the Act if, in the opinion of the Minister, the exemption is necessary for a medical or scientific purpose or is otherwise in the public interest.”¹²

The rest of the document “is intended to clarify the requirements and terminology found in section 56 of the CDSA and to explain the application process to obtain an exemption for a scientific purpose for a pilot SIS research project.”¹³

Participants at the 16-17 December 2002 meeting that reviewed a first draft of the document criticized as unnecessary some of the elements that, according to the document, should be contained in the application to Health Canada. Some, but not all, of their comments were taken into account in the preparation of the

“living document” as it has now been released.

Importantly, the document states that “Health Canada will aim to complete its review within 60 days and inform the Applicant of the outcome of the review.”¹⁴ It is expected that Vancouver may submit an application as early as February 2003. Canada’s first SIS(s) could therefore open by the end of April 2003.

— Ralf Jürgens

Ralf Jürgens is the Executive Director of the Canadian HIV/AIDS Legal Network. He can be reached at ralfj@aidslaw. A detailed review of new developments in the area of SISs in Canada will be published in the next issue of the *Review*.

¹ R Elliott, I Malkin, J Gold. *Establishing Safe Injection Facilities in Canada: Legal and Ethical Issues*. Montréal: Canadian HIV/AIDS Legal Network, 2002 (available via www.aidslaw.ca/Maincontent/issues/druglaws.htm).

² Ibid at 54 (recommendation 2).

³ Ibid at 55 (recommendation 4).

⁴ Health Canada (Drug Strategy and Controlled Substances Programme, Healthy Environments and Consumer Safety Branch). Application for an Exemption Under Section 56 of the *Controlled Drugs and Substances Act* for a Scientific Purpose for a Pilot Supervised Injection Site Research Project. Interim Guidance Document. Ottawa: Health Canada, 29 December 2002 (draft 5.1).

⁵ Email to participants at the 16-17 December meeting by Beth Pieterston, Acting Director General, Drug Strategy and Controlled Substances, Health Canada, dated 31 December 2002.

⁶ Interim Guidance Document, supra, note 4, para 1.

⁷ Available via www.aidslaw.ca/Maincontent/issues/druglaws.htm.

⁸ Interim Guidance Document, supra, note 4 at 2 (para 2), with reference to Supervised Injection Sites: Minimum Criteria for Pilot Projects. Task Group on Supervised Injection Sites, 13 December 2001.

⁹ Ibid at 3.

¹⁰ See supra, note 1 at 36-44.

¹¹ Supra, note 4 at 3.

¹² Ibid.

¹³ Ibid at 5.

¹⁴ Ibid at 12 (para 7.1.5).

Minister Reaffirms Commitment to Provide Medical Marijuana, but Delays Continue

Amid ongoing doubts about the federal government’s commitment to provide marijuana for medical use, the first Canadian clinical trial of smoked cannabis has been launched, and a Senate committee has released its controversial and much-anticipated report.

Health Canada has been criticized for appearing to backpedal on a commitment to distribute Canadian-grown cannabis for therapeutic purposes. Health Minister Anne McLellan has responded to these criticisms, claiming that the government’s position has not changed, and that the delays are due to unanticipated quality-control issues with the crop produced by Prairie Plant Systems Inc in Flin Flon, Manitoba.

In a letter to the press dated 28 August 2002, the Minister reaffirms the government’s commitment to the two “parallel tracks” of the medical marijuana program: research to provide scientific evidence of marijuana’s risks and benefits, and the Marijuana Medical Access Regulations, which allow authorized people to possess and cultivate marijuana for medical purposes.¹ However, uncertainty still surrounds the question whether

Health Canada intends to make the Flin Flon crop available for distribution to people authorized to use marijuana under the regulations (or whether the crop will be used solely for research).

Due to the unsuitability of the Canadian crop, the first Canadian clinical trial of smoked cannabis for people with HIV/AIDS, announced in October 2002 by the Community Research Initiative of Toronto and St Michael’s Hospital, is using material from the US National Institutes of Drug Abuse. The study is investigating the safety and efficacy of smoked cannabis for appetite stimulation and weight gain in people with HIV. The 32-patient pilot study should conclude within six to 12 months and should provide data that will help design a larger and more conclusive clinical trial.

The Nolin Report

The paradox of Health Canada's insistence on further clinical research, while failing to provide

"It is time to recognize what is patently obvious: our policies have been ineffective, because they are poor policies."

Canadian-grown research-grade marijuana, is only one of many issues raised by the report of the Senate Special Committee on Illegal Drugs, released in September 2002.² The committee, chaired by Senator Pierre Claude Nolin, was mandated to examine the social and health impacts of cannabis use, as well as Canadian and international policies and approaches toward cannabis. The committee's report, which fundamentally challenges the federal government's approach to cannabis use and to cannabis users (both therapeutic and recreational), has surprised many people and sparked considerable debate. Criticized by some as being too radical, the report's recommendations have been applauded by many others.

Noting that billions of dollars in spending have failed to significantly affect the level of cannabis use in Canada, the Nolin report asserts that "it is time to recognize what is patently obvious: our policies have been ineffective, because they are poor policies."³ In 11 sweeping recommendations, the report proposes replacing Canada's current prohibitionist stance with policies and practices that recognize that "used in moderation, cannabis in itself poses very little danger to users and to

society as a whole."⁴ The report says that Canada should focus on preventing and treating risky and excessive use, and on more comprehensive and integrated research. Particularly relevant for people with HIV/AIDS is the Nolin report's critique of the regulations governing therapeutic cannabis use.

The Marihuana Medical Access Regulations

The Marihuana Medical Access Regulations (MMAR), in effect since July 2001, define the process by which Canadians may apply for the legal right to possess and use marijuana to treat HIV or other medical conditions. These regulations have been widely criticized as unwieldy and overly restrictive – notably in a civil suit currently before the courts.⁵ Applicants are required to obtain a detailed recommendation from a medical practitioner – something most physicians are unwilling to provide. Applicants must either grow their own plants or designate another individual to do so for them. Cultivation on rented property requires the landlord's permission as well. Buyers' clubs that provide marijuana to people with medical conditions remain illegal under the regulations.

The Nolin report's analysis of the MMAR concludes that "the refusal of the medical community to act as gatekeepers and the lack of access to legal sources of cannabis appear to make the current regulatory scheme an 'illusory' legislative exemption and raise serious Charter implications." The report states that "the MMAR are not providing a compassionate framework for access to marijuana for therapeutic purposes and are unduly restricting the availability of marijuana to patients who may

receive health benefits from its use." According to the report, "changes are urgently needed."⁶

While the legal and political debates continue, patients and caregivers continue to be vulnerable to legal action. In August 2002, the Toronto Compassion Centre (a cannabis buyers' club in operation since 1997) was raided and shut down by police. Four of the Centre's personnel face criminal charges. Meanwhile, a group of individuals in Vancouver has opened what it calls Canada's first marijuana factory. The facility intends to process marijuana plants into "THC balls" – concentrated pellets of tetrahydrocannabinol, the active ingredient in marijuana – that can be incorporated into food. Besides distributing its product to individuals with MMAR exemptions, the factory may also provide it to others who require it for medical reasons but have not received the exemption.

– Derek Thaczuk

Derek Thaczuk is the Treatment Resources Coordinator at the Toronto People With AIDS Foundation, and until recently was the Chair of the Community Research Initiative of Toronto. He can be reached at derekt@pwatoronto.org.

¹ Both the letter and the regulations are available on the website of the Office of Cannabis Access (Health Canada) via <http://www.hc-sc.gc.ca/hecs-sesc/ocma>. Click on "What's New" for the letter and on "Legislation" for the regulations.

² *Cannabis: Our Position for a Canadian Public Policy*. Senate Special Committee on Illegal Drugs, September 2002. The full report, which consists of a summary report and four additional volumes, is available on the Parliament of Canada website via www.parl.gc.ca. Click on "Committee Business."

³ Summary report at 36.

⁴ *Ibid* at 42.

⁵ See L. Scanlon, Government delays release of medical marijuana supply, *Canadian HIV/AIDS Policy & Law Review* 2002; 7(1): 34-35.

⁶ Summary report at 23.

Canada Will Have a National HIV Vaccine Plan

Health Canada announces that a national HIV vaccine plan will be developed in consultation with key stakeholders and that it will contribute to the global vaccine effort.

Health Canada has agreed to develop a national HIV vaccine plan. The Canadian HIV/AIDS Legal Network called for the development of such a plan in a report issued in June 2002.¹

In an address to an international conference in July 2002,² Dr Paul Gully, Associate Director General, Population and Public Health Branch, said that “Health Canada welcomes this report and looks forward to entering into a formal dialogue with key stakeholders on this important matter.” He added that

[t]ogether, we will develop a plan that will focus on vaccine production and equitable distribution. This plan will support the global vaccine effort and contribute to a

better understanding of the complex legal, ethical and human rights issues involved in addressing access to vaccine and treatment for people living with HIV/AIDS, nationally and globally.³

Canada currently spends only a small portion of its \$42.2 million annual domestic HIV/AIDS budget on vaccines and vaccine research. In its report, the Network called for a commitment to an accelerated and sustained program of HIV vaccine research in Canada; a substantial increase in funding for HIV vaccine research; and the development, by 1 October 2003, of a Canadian HIV Vaccine Plan containing both a development and a delivery component.

Health Canada has not indicated a date by which the plan will be completed. However, it has announced the formation of an internal working group on HIV Vaccine Development and Equitable Distribution. The working group will develop a mechanism for consultation and collaboration.⁴

– David Garmaise

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

² *Putting Third First: Vaccines, Access to Treatments and the Law*, Satellite Meeting at the XIV International AIDS Conference, 5 July 2002, Barcelona, Spain, organized by the Network, the AIDS Law Project, South Africa and the Lawyers Collective HIV/AIDS Unit, India, and co-hosted by UNAIDS. Proceedings are available at www.aidslaw.ca/barcelona2002/e-barcelona2002.htm. See also “Advancing Research and Access to HIV Vaccines: A Framework for Action” at page 99 of the Barcelona 2002 supplement in this issue.

³ A copy of Dr Gully’s opening remarks to the *Putting Third First* satellite meeting are on file at the Canadian HIV/AIDS Legal Network.

⁴ Health Canada. HIV/AIDS Communiqué, 2002; 1(1), available online (www.hc-sc.gc.ca/hppb/hiv_aids/can_strat/pdf/communique.html).

Senate Committee Calls For Major New Spending on Health Care

Senator Michael Kirby’s committee says that the federal government should invest \$6.5 billion more each year. It calls for the establishment of new national programs to pay for catastrophic drug costs and to expand home and palliative care.

A Senate committee has called for major new investment in health care, including the establishment of a national program to help pay catastrophic drug costs, a national home-care program, and a national palliative-care program.¹ The committee, chaired by Senator Michael Kirby,

issued its report in October 2002. It is the first of two major health-care studies to be released this fall; the Commission on the Future of Health Care in Canada, headed by former Saskatchewan Premier Roy Romanow, was released on 28 November 2002.

No Canadian should suffer undue financial hardship as a result of having to pay health-care bills, including prescription drug expenses.

The committee says that no Canadian should suffer undue financial hardship as a result of having to pay health-care bills, including prescription drug expenses. It says that 600,000 Canadians currently have no protection against catastrophic prescription drug costs and that 100,000 Canadians currently have annual drug expenses exceeding \$5,000.

The committee recommends that the federal government fund most catastrophic prescription drug costs, which the committee defines as annual costs exceeding \$5000. Under the committee's proposal, the first \$5000 would be covered by a combination of provincial/territorial and private insurance, as well as individual contributions (individual expenses would be capped at 3 percent of family income). Of costs over \$5000, the federal government would pay for 90 percent, with the remaining 10 percent paid through provincial/territorial or private insurance.

The committee says that this program will cost \$500 million annually. The committee also calls for the creation of a national drug formulary to ensure uniformity of coverage across the country. (See "Provinces Create Centralized System for Assessing New Drugs," below.)

The committee calls for the creation of a national post-acute health program, funded by the federal government and the provinces/territories on a fifty-fifty basis. This program would fund home-care expenses incurred within a three-month period following discharge from a hospital, provided that care started within 30 days of discharge. The committee estimates that this program would cost \$550 million annually.

The committee also recommends that a national palliative-care program be created, funded by the federal government and the provinces/territories on a fifty-fifty basis. The committee recommends that the federal government contribute \$250 million a year to this program.

The committee recommends instituting a health-care guarantee under which maximum waiting times

would be established for all procedures and treatments. When the maximum waiting time is reached, the government would pay for treatment in another jurisdiction, including, if necessary, another country.

The committee also says that Canada should increase its spending on health research to one percent of total health-care spending, which would require an additional investment of \$440 million annually by the federal government.

Other recommendations made by the committee include:

- changes in the way hospitals are funded, and measures to increase the efficiency of hospitals (the committee expressed support for more competition among hospitals);
- changes in the way doctors are paid;
- more control by regional health authorities over health-care spending;
- a national system of electronic health records;
- measures to safeguard the protection of personal health information;
- measures to address the problem of health-care human-resource shortages;
- considerable new investment in health-care technology; and
- the appointment of a health-care commissioner.

The committee recommended that the federal government spend in all an additional \$6.5 billion annually on health care. Of this amount, it says that \$1.5 billion should come from increased federal government transfers to the provinces and territories, and \$5 billion from new tax revenue (either by increasing the Goods and

Services Tax or by creating a national health-care premium, the amount of which would vary by income).

Most non-governmental organizations working in health care welcomed the committee's proposals. However, some concerns were expressed that the committee's recommendations on hospital restructuring would open the door to more for-profit health care.

– David Garmaise

Editor's note: On 28 November 2002 the Final Report of the Commission on the Future of Health Care in Canada (the Romanow report) – a second major national review of Canada's health-care system – was released.² It recommends, among other things, increased and targeted funding for health care; improved primary health care and prevention; coverage for home care for people with mental illnesses, after acute care, and in palliative care for the last six months of their lives; a national formulary for prescription drugs and funding to reduce disparities in catastrophic coverage for prescription drugs across Canada; and consolidated funding for Aboriginal health services. The report also calls for a sixth principle – accountability – to be added to the *Canada Health Act* and for the establishment of a new Health Council of Canada to measure and report on the performance of the health system. In the next issue of the *Review* we hope to publish a feature article summarizing the significance of the Romanow report for people with HIV/AIDS and assessing the response of first ministers in Canada to the report.

¹ *The Health of Canadians – The Federal Role: Final Report on the State of the Health Care System in Canada (Volume Six: Recommendations for Reform)*. Standing Senate Committee on Social Affairs, Science and Technology, October 2002. The full report, as well as a highlights version, are available on the Parliament of Canada website via www.parl.gc.ca. Click on "Committee Business."

² RJ Romanow. *Building on Values: The Future of Health Care in Canada – Final Report*. Ottawa: Commission on the Future of Health Care in Canada, 2002 (www.hc-sc.gc.ca/english/pdf/care/romanow_e.pdf).

Provinces Create Centralized System for Assessing New Drugs

Provincial health ministers have created a common drug-review process for assessing whether new drugs should be placed on provincial formularies. The new system may save money, but will it improve access?

A new, centralized plan for assessing new drugs to determine if they should be listed on provincial formularies has drawn mixed reviews from health-care stakeholders. At the annual Federal/Provincial/Territorial Conference of Health Ministers in September 2002, ministers announced that the Canadian Coordinating Office for Health Technology and Assessment (CCOHTA) will take over responsibility for assessing new drugs early in 2003.¹

Before a new drug is approved for sale in Canada, the Therapeutic Products Directorate of Health Canada conducts a review to determine whether the drug is safe and effective. Once a drug is licensed, it is the prerogative of provinces to determine whether it will be listed on provincial formularies. Formulary listing means that, for some people, a provincial health plan will pay all or a portion of the cost of a drug that has been prescribed. This determination is based on a broader evaluation of not

just the efficacy of a drug, but also its cost-effectiveness in relation to other products and overall health-care spending.

At present, these assessments are conducted independently by each province, with no interprovincial coordination. As a result, there is no consistency across Canada with respect to what is covered by provincial plans. The system of independent provincial reviews also leads to duplication of work across the country. The health ministers said that their objective was to eliminate this duplication and to save health-care dollars in the process. However, the CCOHTA will only have the authority to make recommendations; whether a new drug is included on provincial formularies will still be up to each province to decide.

While they applaud the potential savings, treatment activists and the drug industry have expressed a variety of concerns about the new process.

- Because the criteria that the CCOHTA will apply in its assessment are not known, there is concern that the new system could, if it excludes drugs that at present at least some provinces are covering, in fact reduce access to certain drugs.
- Because each province will still decide whether a new drug makes it onto its formulary, the patchwork system that currently exists across the country may be perpetuated.
- New drugs may not be reviewed in a timely fashion. National regulators do not have a stellar record when it comes to meeting their own targets for making decisions. For some provinces, this might mean slower formulary approvals.
- The new plan has been developed with no input from consumers or industry.

Meanwhile, a Senate committee has recommended the establishment of a national drug formulary. (See “Senate Committee Calls For Major New Spending on Health Care,” above.)

– Glen Hillson

¹ The announcement is available on the website of the Canadian Intergovernmental Conference Secretariat (www.scics.gc.ca/cinfo02/830756004_e2.html).

Regulators Deny Access to Experimental Hepatitis C Drug

An application for access to an experimental hepatitis C drug under Canada’s Special Access Programme has been turned down. In the process, Canada’s drug regulators have created discomfort and uncertainty about how the Special Access Programme is managed.

In a controversial decision, the Therapeutics Products Directorate

(TPD) of Health Canada has denied an application under its Special

Access Programme (SAP) for an experimental hepatitis C drug. CBC Radio reported in September 2002¹ that the TPD turned down a request for access to an herbal tonic developed by AMMA Corporation, a small Calgary-based company.

According to unofficial reports, there is anecdotal evidence that the tonic offers benefit to hepatitis C sufferers. At least seven Canadians have

used the tonic but are forced to travel to Peru for additional treatment because of the TPD ruling. Featured in the CBC story was a 14-year-old boy in British Columbia, who is apparently one of the seven Canadians who have taken the herbal tonic at a laboratory site in Peru where experiments are being conducted.

AMMA Corporation is sponsoring the development of the tonic and claims that all study participants have experienced a reversal of symptoms. However, there is no published information about the design of the experiments, the outcomes, the patients' characteristics, or the composition of the tonic. AMMA says that the story has generated a flood of requests for the tonic from people with hepatitis C. AMMA says it has enough tonic only to ensure an uninterrupted supply to those already receiving it by traveling to Peru.²

According to the CBC report, the TPD based its decision on a lack of information about the tonic. The purpose of the SAP is to grant approval for access to medicines that are not

licensed for sale in Canada or available through clinical trials or compassionate-access programs. The SAP is intended to help facilitate access for patients with "serious or life-threatening conditions when conventional therapies have failed, are unsuitable, or unavailable."³ SAP applications are assigned a high priority and are usually processed in one to three days. In granting special access, the TPD does not recommend use of the drug or render an opinion "that the drug is safe, efficacious or of high quality."⁴

In order for special access to be considered, a physician must complete and submit a form.⁵ The physician must explain why a particular drug is needed, why this drug is the best choice, what other therapies have been considered and/or tried, and why no other drug is suitable. The physician must also provide sources of information that support the physician's decision.

The controversy created by the refusal stems in large measure from the lack of clarity in the TPD's own policy. While on the one hand the

TPD says that it is responsible for determining whether a drug is sufficiently safe to grant special access, it also says that an SAP authorization does not constitute an opinion or statement that a drug is safe. It is not clear just what standards the TPD applies when deciding whether a drug is sufficiently safe for special access. Moreover, given the short turnaround time for requests under the SAP, and no apparent requirement to submit data about the drug being requested, a comprehensive review of the drug is not possible.

– Glen Hillson

¹ Canadian Broadcasting Corporation. Medical standoff threatens teen's life. 20 September 2002. Text available on the CBC British Columbia site at <http://vancouver.cbc.ca>.

² J Matthews. Hep C sufferers swamp trial drug producers. 23 September 2002. Text available on the site of CBC British Columbia at <http://vancouver.cbc.ca>.

³ Quoted from the description of the SAP on Health Canada's website at www.hc-sc.gc.ca/hpb-dgps/therapeut/htmleng/sap.html.

⁴ See "Special Access Programme (SAP) Instructions for Making a Special Access Request" on the SAP webpage, *supra*, note 3.

⁵ See "Special Access Request Form" on the SAP webpage, *supra*, note 3.

Medical Association Calls for Routine HIV Testing of Pregnant Women

The Canadian Medical Association says that routine HIV testing of pregnant women is necessary because there are still babies being born with HIV infection. Critics respond that routine testing is the same as mandatory testing, that there is no reason to waive the requirement for informed consent accompanied by pre-test counselling, and that physicians need to do a better job of offering HIV testing to pregnant women.

In August 2002, the annual general meeting of the Canadian Medical Association (CMA) adopted a motion calling for routine prenatal HIV screening of all pregnant women. CMA delegates said that routine testing is necessary because there is no standard federal or provincial policy on testing pregnant women for HIV, and that it is unacceptable that babies in Canada are born with HIV despite the availability of effective pre- and postnatal treatment regimens.

Routine testing means that the HIV test would be included on laboratory forms along with a battery of other tests normally given during prenatal care. Theoretically, pregnant women would be able to opt out of the HIV test when they are asked to give their consent for all the tests listed on the laboratory form. However, critics of routine testing say that placing the HIV test on a laboratory form with other tests may only imply consent. They hold that informed consent, accompanied by pre-test counselling, should be given specifically for the HIV test; if specific, informed consent is not obtained for an HIV test, then routine testing is tantamount to mandatory testing.

Critics also argue:

- that informed consent with pretest counselling is the current standard of professional care in Canada for all HIV testing;
- that there is no valid reason why this requirement should be abrogated in the case of pregnant women;

- that physicians need to ensure that all pregnant women are offered HIV testing; and
- that it is particularly important to counsel a pregnant woman and to obtain her informed consent because the sooner she is informed about the advantages and disadvantages of testing and available treatments, the more likely she is to make decisions that will ultimately benefit herself and her child.

Both the Canadian HIV/AIDS Legal Network and the Canadian AIDS Society have spoken out against the routine testing of pregnant women.¹ As well, in its guiding principles for HIV testing of women during pregnancy, published in March 2002, the Federal/Provincial/Territorial Committee on AIDS say that “voluntarism, confidentiality and informed consent” should guide policy and practices in this area.² The committee did not take a position specifically on routine testing.

The Canadian Public Health Association (CPHA) also supports

voluntary testing. In 1998, the CPHA passed a resolution calling for increased testing of HIV, but rejecting mandatory testing and upholding the principles of confidentiality.³ The association recommended that further efforts be undertaken to increase voluntary testing and called for the inclusion of anonymous-testing sites as a prevention tool to encourage individuals to test for HIV.

– Paul Kenney

Paul Kenney is the Director of the Canadian HIV/AIDS Clearinghouse. He can be reached at pkenney@cpha.ca.

¹ See L. Stoltz, L. Schap, *HIV Testing and Pregnancy: Medical and Legal Parameters of the Policy Debate*. Montréal: Canadian HIV/AIDS Legal Network, 1999 (www.aidslaw.ca/Maincontent/issues/testing/e-preg.pdf). See also the Canadian AIDS Society's position on HIV Testing of Pregnant Women at www.cdnaids.ca/web/position.nsf/cl/cas-pp-0004.

² Guiding principles for human immunodeficiency (HIV) testing of women during pregnancy-2002. *Canada Communicable Disease Report* 2002; 28(13): 105-107 (available via www.hc-sc.gc.ca/pphb-dgspsp/publicat/ccdr-mmtc).

³ *HIV & Public Health Policy*. Ottawa: Canadian Public Health Association, 1998.

HIV Study among Pregnant Aboriginal Women Raises Concerns

An unlinked HIV seroprevalence study among pregnant Aboriginal women in BC reveals an alarming trend and raises ethical questions about certain types of research in Aboriginal communities.

Controversy is brewing over a four-year seroprevalence study being conducted among Aboriginal women for Health Canada and the BC First Nations Chiefs' Health Committee. Blood samples from First Nations women undergoing routine prenatal

blood tests are being tested for HIV and HTLV-1 (human T-lymphotropic virus, type 1) after information about the identity and community of the donor have been removed. Women can refuse to participate in the study.¹

So far, the rate of HIV in pregnant

Aboriginal women in the study is about seven times higher than in pregnant women as a whole. Blood samples from 10 of the approximately 3200 Aboriginal women in the study were found to be HIV-positive.² The study has raised concerns because it is not possible to notify the women from whom these blood samples were taken and to provide them with treatment and support.

Activists differ in their views of the study.³ Some argue that the study does little to help the individuals and communities being studied and will only add to their fear of negative stereotypes. They claim that

Aboriginal women may avoid prenatal testing and care, thereby adversely affecting their health and that of their child. They point out that when a similar study was conducted in Ontario, participation in prenatal examinations by Aboriginal women dropped from 85 to 25 percent. Others welcome the study as a way to identify hidden epidemics in Aboriginal communities. They argue that such studies will provide much-needed information to guide education and prevention efforts and to press for more government funding for HIV prevention.

Whatever their position on this issue, Aboriginal AIDS activists agree that efforts need to be made to encourage women to be tested for HIV. In response to the findings of this survey, an advertising campaign on Aboriginal People's Television Network and local BC cable networks is encouraging pregnant women to be tested for HIV.

— Kim Thomas

¹ L. Brown. *What Pregnant First Nations Women Should Know About HIV and HTLV*. First Nations Chiefs' Health Committee. West Vancouver, BC, no date.

² Canadian Press. HIV threat high for pregnant aboriginal women. 22 October 2002 (www.globeandmail.com/servlet/ArticleNews/front/RTGAM/20021022/whiv1022a/Front/homeBN/breakingnews).

³ P. Weinberg. Pregnant Aboriginal anonymously tested for HIV. 19 September 2002 (www.ipsnews.net/).

Vancouver Police Raid Needle Exchange Run by Drug Users

The police claimed that drug trafficking was going on at the needle exchange run by the Vancouver Area Network of Drug Users, but they failed to provide any evidence to that effect. The police later apologized for their remarks and the exchange re-opened.

On the evening of 31 May 2002, the Vancouver Police Department (VPD) sent nine police officers, a paddy wagon, and three police cars to a small needle exchange table on the corner of Main and Hastings Streets in Vancouver's Downtown Eastside. The table was being operated by the Vancouver Area Network of Drug Users (VANDU). Police forced the VANDU volunteers to close the needle exchange and seized the equipment used to operate it. VANDU had operated the needle-exchange table for almost two years, with funding from the Vancouver Coastal Health Authority, and was dispensing about 1200 needles a day.

At first, the police raid was described by the VPD as a response to drug trafficking by VANDU volunteers who staffed the tables. Deputy Police Chief Gary Greer told a local radio station that "more drugs than needles were exchanged." He added: "If people are involved in drug trafficking, and they try to include that in somehow assisting in exchange of needles, I'm sorry, we're not going to make any apologies for going after drug traffickers."¹

However, no VANDU volunteers were arrested or charged with any offence before, during, or after the raid. In fact, the only legal basis for the police raid appeared to be a bylaw infraction ticket that was issued for "interfering with the flow of pedestrian traffic." That such a ticket could be issued against a needle exchange

located in the middle of what has been referred to as the largest open illegal drug market in North America was, to say the least, ironic. What made the raid particularly ominous was the fact that other non-permitted uses on the corner, such as a nurse's table and a portable toilet service offered by the Health Authority, were not targeted at all.

VANDU approached Pivot Legal Society for help, and lawyer John Richardson was retained to launch a legal campaign to ensure the safe re-opening of the table. At the same time, despite constant police surveillance, members of the Anti-Poverty Committee opened another needle exchange table at the same corner to ensure that the much-needed service was continued.

Pivot began its action by initiating a dialogue with the Vancouver Police Board, the body responsible for overseeing the VPD. Richardson wrote letters and spoke before the Board, emphasizing concerns about the raid and other incidents in which VPD officers appeared to take actions that clearly violated the Vancouver Police Board's policies supporting harm reduction. Pivot proposed that the VPD and VANDU enter into an administrative agreement to allow the renewed operation of the exchange, and presented a proposed draft agreement as a basis for negotiation.

Pivot also focused on specific illegalities connected to the police raid. Richardson wrote to the VPD asking

what lawful authority the police had relied upon when it seized the property used to operate the exchange. The letters demanded the immediate return of the property if it was seized without lawful authority. Pivot also arranged VANDU to retain, pro bono, a private bar lawyer, Cameron Ward, and worked with him on the preparation of a lawsuit against Deputy Police Chief Greer for slander over his comments about the exchange. Ward wrote to Greer, demanding that he provide a written apology or face a defamation lawsuit.

This appeared to provoke a softening of the police position, and the needle exchange equipment was returned shortly thereafter.

More than a dozen letters concerning the needle exchange had been exchanged between the VANDU lawyers and the various authorities when, on 16 July 2002, Deputy Chief Greer delivered to VANDU a written apology for his defamatory statements about the exchange table. Eight weeks after the initial raid, the VANDU needle exchange was re-opened, with a

newly designed table and increased funding from the Vancouver Coastal Health Authority. While there were reports that the police threatened to shut the table down again in October, this did not happen.

— Thomas Kerr and Evan Wood

Thomas Kerr is a regular correspondent for Canadian News. Evan Wood is health associate at the BC Centre for Excellence in HIV/AIDS. He can be reached at ewood@hivnet.ubc.ca.

¹ Deputy Chief Greer's comments were recorded and broadcast by CKNW Radio shortly after the raid.

Studies Document Gender Differences in HIV Risk and Impact

According to new studies, women account for half the new HIV infections in Aboriginal people, and women who inject drugs are at higher risk than their male counterparts.

Several studies published in 2002 documented gender differences in Canada in HIV-related risks and impact, and highlighted the need to adopt a gender perspective on HIV prevention and treatment strategies. The studies were published by the Atlantic Centre of Excellence for Women's Health (ACEWH) and the Commonwealth Secretariat¹ as part of a manual on gender mainstreaming in HIV/AIDS.²

Despite an overall decrease in the number of newly reported HIV infections since 1995, the rate of infection among women has risen steadily. The studies revealed that women account for almost 50 percent of new HIV infections in Aboriginal people (com-

pared to 20 percent in the non-Aboriginal population), and that injection drug use is a growing risk factor for women. The proportion of positive HIV tests among women attributable to injection drug use rose from about 32 percent prior to 1994 to about 50 percent in the period 1995-1999. The researchers suggest that women who inject drugs are more likely than their male counterparts to share needles and syringes; to share other injection materials such as water, cookers, and cottons; and to report sharing of needles and syringes with a sexual partner.

The manual also contains the results of studies conducted among pregnant women and female prosti-

tutes. It provides a number of case scenarios from Canada and abroad that document best practices in addressing the various gender, social, and economic factors in preventing HIV/AIDS, and it includes a broad list of gender-related tools and online resources.

The document is intended for use by health departments, policymakers and planners, as well as others involved in HIV/AIDS-related education and health-service delivery. For more information, contact Dr Jacqueline Gahagan of ACEWH (jacqueline.gahagan@dal.ca).

— Caroline Ploem

¹ The Commonwealth Secretariat is the principal administrative organization of the (British) Commonwealth.

² Commonwealth Secretariat and the Atlantic Centre of Excellence for Women's Health. *Gender Mainstreaming in HIV/AIDS: Taking a Multisectoral Approach*. London: 2002. Copies of the manual can be obtained for CDN\$25 (inclusive of taxes and shipping) through the ACEWH (tel: 902 470-6739 or via www.medicine.dal.ca/acewh).

In Brief

RCMP Lay Charges in Tainted-Blood Scandal

The RCMP has laid 32 charges with regard to the distribution of contaminated blood products in Canada in the mid-1980s.¹ Almost all the allegations relate to the distribution of Factorate, a blood-clotting product produced by Armour Pharmaceutical Company, when it was known that the product might be infected with HIV.²

Those charged include a former director of the Bureau of Biologics at Health Canada, a former chief of the Blood Products Division of the Bureau of Biologics, a former director of the Canadian Red Cross Society's Blood Transfusion Service, the Canadian Red Cross Society, Armour Pharmaceutical Company, and a former vice-president of scientific and regulatory affairs at Armour. The charges include numerous counts of criminal negligence causing bodily harm and common nuisance by endangering the public under the *Criminal Code* of Canada, and one count of failure to notify under the Food and Drug Regulations.

Thousands of people, many of them hemophiliacs, were infected with HIV and hepatitis C through infected blood products in the mid-1980s. The scandal was the subject of a federal commission of inquiry, headed by Mr Justice Horace Krever, from 1993 to 1997. Mr Krever's report,³ released in November 1997, made 50 recommendations, but did not apportion blame or make criminal allegations. In December 1997, the RCMP launched their own inves-

tigation to determine if criminal charges should be laid.

– *Theodore de Bruyn*

Spitting Incident Leads to Renewed Calls for Mandatory Testing

A spitting incident in Edmonton, Alberta, has led to more calls for legislation that would permit mandatory blood testing of any person who exposes police officers, firefighters, other emergency personnel, or health-care providers to bodily fluids. In July 2002, a man spat on a female police officer. He later voluntarily submitted to blood tests for HIV.⁴ Nevertheless, Edmonton police and emergency health-care providers in the city expressed the need for mandatory testing legislation.

Those in favour of the proposed legislation argue that mandatory testing would alleviate unnecessary stress and allow for timelier and better decisions about prophylaxis. Critics contend that implementing mandatory testing would not protect workers from occupational exposure, and that other measures – such as ensuring universal precautions and legislating the use of safer needles and syringes in health-care settings – would be more effective. Opponents also hold that mandatory testing grossly infringes on the source person's basic constitutional rights to liberty, security of the person, and privacy, as well as the legal requirement for informed consent to any medical procedure.

The government of Alberta currently regards this as a public health issue rather than one requiring crimi-

nal legislation.⁵ In Ontario, a private members bill authorizing the taking of blood samples in certain circumstances for the purpose of testing for viruses that can cause certain communicable diseases was adopted in December 2001⁶ and will come into effect on 1 May 2003. The government of Ontario has been conducting limited consultations on the regulations that will accompany the new legislation. A similar private member's bill was introduced in the House of Commons in 2001, but died in 2002, after the Standing Committee on Justice and Human Rights referred the issue to the Uniform Law Council of Canada and the Council of Justice Ministers for consideration.⁷

– *Rebecca Scheer*

Alberta Gets a Second Methadone Clinic

Alberta's second methadone maintenance treatment (MMT) clinic opened in Red Deer in November 2002. Previously, the province's only MMT clinic was located in Edmonton and clients wanting to access treatment faced a long waiting period. The new clinic, referred to as the Central Alberta Methadone Program (CAMP), is operated by a private group of professionals, known as Meta Clinic, who also operate two private MMT clinics in BC.

CAMP will address a growing injection drug problem in the Red Deer region where morphine has become the largest opiate addiction.⁸ The Central Alberta AIDS Network needle exchange reports that demand

for clean needles jumped from 2000 a month in 1999 to an average of 8000 a month in 2002 – a per capita rate that is higher than Calgary’s and comparable with Edmonton’s.⁹

In addition to providing a means of connecting clients with counselling and resources, MMT programs have been credited with decreasing the use of opiates such as heroin and morphine, reducing crime, and lowering infection rates of HIV and hepatitis C. Meta Clinic and officials with the Alberta Alcohol and Drug Abuse Commission, the agency that operates the MMT clinic in Edmonton, have both indicated that they are considering opening a clinic in Calgary.¹⁰

– Rebecca Scheer

Youth Prevented from Giving Out Condoms at a Catholic Festival

Toronto police stopped a man from distributing condoms during World Youth Day (WYD) events in Toronto in July 2002. WYD is a celebration of Catholic youth. Milton Chan, a 23-year-old member of an organization of Catholics called Challenge the Church, was distributing pamphlets and condoms to WYD participants, inviting them to an Alternative Youth Day event to discuss issues such as the church’s stance on contraception, safer sex, and homosexuality. Mr Chan was approached by a police officer and told that there were complaints about him handing out condoms outside a WYD event. The police told Mr Chan that what he was doing was “inappropriate for what they’re trying to come across with today”¹¹ and asked him to leave. Mr Chan left, returning later to hand out the pamphlets without condoms.

Media reports of the incident led to some questioning of the police actions. Concerns were expressed that the police were acting as agents of the Church. Chan filed a complaint with Toronto police, alleging misconduct on the part of the officer. Under the police complaints system, the police conduct their own investigation of complaints, with a heavy emphasis on informal resolution of complaints. The investigator assigned to the case indicated that it would probably be several months before any preliminary findings would be available.

– Matthew Perry

NWT Prohibits Discrimination Based on Gender Identity

The Northwest Territories has become the first jurisdiction in Canada to prohibit discrimination on the grounds of gender identity, thus providing transgendered people with explicit protection from discrimination. Bill 1, the *Northwest Territories Human Rights Act*,¹² was adopted on 30 October 2002. The Act contains a number of other prohibited grounds of discrimination, including sexual orientation. It also sets up a human rights commission.

Two organizations representing lesbians, gays, bisexuals, and transgendered people, OutNorth (from the Northwest Territories) and EGALE Canada, appeared as witnesses before the legislative committee studying the new bill to argue for the inclusion of gender identity.

With the passage of the Act, discrimination against lesbians, gays, and bisexuals is now prohibited in every province and territory in Canada except the new territory of

Nunavut, which is considering enacting human rights legislation.

– David Garmaise

¹ Royal Canadian Mounted Police. News release: RCMP blood task force lays criminal charges. 20 November 2002 (www.rcmp-grc.gc.ca/news/nr-02-26.htm).

² A Picard. RCMP lay 32 charges in tainted-blood case. *Globe and Mail*, 21 November 2002: A1, A6.

³ *Final Report. Commission of Inquiry on the Blood System in Canada*. Ottawa: Minister of Government Works and Public Services, 1997 (available via www.hc-sc.gc.ca/english/protection/krever/).

⁴ J Loome. Man who spat on officer will have tests. *Edmonton Sun*, 30 July 2002: 15.

⁵ Letter to Kenneth Morris, President of the Alberta College of Paramedics, from the Honourable Gary Mar, Minister of Health and Wellness (Government of Alberta), 19 September 2002, on file.

⁶ R Carey. Ontario adopts “blood samples” legislation. *Canadian HIV/AIDS Policy & Law Review* 2002; 6(3): 39-40.

⁷ T de Bruyn, R Elliott. Compulsory HIV testing after an occupational exposure. *Canadian HIV/AIDS Policy & Law Review* 2002; 6(3): 1, 24-31 at 25.

⁸ A Steele. Methadone clinic opens in Red Deer. *Calgary Herald*, 23 September 2002: B1.

⁹ Ibid.

¹⁰ Ibid. T Olsen. Addicts may get injection centre. *Calgary Herald*, 30 August 2001: A1.

¹¹ The police were quoted in a story on CBC Television’s *The National* on 24 July 2002.

¹² The text is available on the website of the NWT Legislative Assembly via www.assembly.gov.nt.ca/.

INTERNATIONAL NEWS

This section provides brief reports on developments in HIV/AIDS-related law and policy outside Canada. Contributors to International News in this issue are Anna Alexandrova, Joanne Csete, Eszter Csernus, Richard Elliott, Michaela Figueira, Jane Hodges, Lisa Oldring, Durojaye Ebenezer Tope, Chris Ward, and Nick Young. 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.

Chinese Scholars Call for AIDS Rules Based on Respect for Individual Rights

In June 2002, the UN Theme Group on HIV/AIDS in China published a comprehensive situation analysis and needs assessment of the HIV/AIDS epidemic in the People's Republic of China (PRC). The report, entitled "HIV/AIDS: China's Titanic Peril," also describes and analyzes current HIV/AIDS legislation and policies. It notes that "laws and regulations that are based on fear and prejudice have contributed to fuelling the epidemic instead of curbing it."¹ The report observes that the targets and goals established in China's five-year Plan of Action (2001-2005) are not consistent with the commitments endorsed in June 2001 at the United Nations General Assembly Special Session on HIV/AIDS. It states that the Plan "continues to present HIV/AIDS as a medical problem, and fails to understand the epidemic as a broader development issue."²

Even where laws could assist, enforcement remains a huge challenge. For example, in 1998 the National People's Congress passed a law prohibiting commercial blood donations for medical purposes. Nonetheless, the illicit and unregulated blood trade, which has rapidly accelerated the spread of HIV infection in China, has continued. When the alarm was sounded by Dr Wan Yanhai, coordinator of the AIZHI (AIDS) Action Project, the government response was to arrest him (see the feature article in this issue on the First Annual Awards for Action on HIV/AIDS and Human Rights).

In the following article, Nick Young, editor of *China Development Brief*, reviews the findings of three studies commissioned by the United Nations Development Programme (UNDP) on the role of the law in response to HIV/AIDS.³

"The core problem in Chinese AIDS law is that people are not treated as principals enjoying rights; they are treated as targets of management."

Chinese laws, regulations, and administrative rulings related to the prevention and control of HIV/AIDS are frequently discriminatory and counterproductive, and should be revised to respect the rights of HIV-positive people and to decriminalize drug abuse and prostitution. These are the main findings of three distinguished Chinese scholars engaged on a UNDP-funded research and advocacy project. In an unusual departure for an exercise of this kind, the commis-

sioned studies go beyond appealing in general terms for “more attention to be paid” to concerns they raise, instead tabling specific proposals for amendments to existing laws and regulations.

Professor Li Dun of Tsinghua University reviewed several hundred legal documents relevant to the management of HIV/AIDS, including laws passed by the National People’s Congress (NPC), “decisions,” “opinions,” and other policy statements with legal force issued by the Communist Party or the State Council, regulations issued by the State Council, administrative rulings issued by government departments, and local regulations issued by provincial and city governments. The reviewed material included specific measures aimed at curbing the spread of AIDS but also those covering medical care, maternal and child health, marriage, social security, litigation, household registration and migration, and information disclosure and access.

Professor Li concludes that “the core problem in Chinese AIDS law is that people are not treated as principals enjoying rights; they are treated as targets of management.” Renowned Chinese Academy of Social Sciences moral philosopher, Qiu Renzong, suggests in a separate paper that policymakers have been influenced by a perceived conflict of interest between the majority of citizens and a minority who indulge in high-risk behaviour. This has encouraged a punitive approach to the latter in order to protect the rights and interests of the majority.

“This is entirely mistaken,” Professor Qiu argues. “Only when we integrate ‘us’ and ‘them,’ ‘the minority’ and ‘the majority’ into ‘ALL’ in our minds can we act as a

whole and win the battle against AIDS.”

Punitive treatment of high-risk groups hinders effective prevention strategies.

Professor Xia Guomei of the Shanghai Academy of Social Sciences assessed the social impact of existing legislation, through interviews with policymakers, officials, health-service staff and AIDS prevention workers, as well as with commercial sex workers, drug users, and HIV-positive people and their families in Sichuan, Yunnan, and Shanghai. Professor Xia documents many instances of HIV-positive people being denied medical treatment, shuffled between hospitals, and enduring gross stigmatization – one interviewee recalled a hospital cashier who used tweezers to accept her payment – partly out of fear and ignorance and partly in pursuance of rules requiring the isolation of AIDS patients. Other examples of active discrimination concerned breaches of confidentiality and failure to disclose test results.

Punitive treatment of high-risk groups hinders effective prevention strategies, Professor Xia found. Sex workers and drug users she interviewed betrayed a high level of ignorance. One karaoke bar worker believed that HIV-positive clients could be identified because they would have “black genitals.” Another thought that transmission could be prevented by “paying attention to hygiene. Pants must be clean. The place to sit has to be clean also ... when you wear a short skirt it is easy

to get infected if you sit on a stool immediately after a venereal disease patient.”

Yet AIDS prevention workers were hampered in providing appropriate information. One reported being told, after sending draft publicity materials for approval by local officials, that “this campaign must be conducted in a quiet place.”

Qiu Renzong’s paper, “A Proposal for Legislative Reform in Relation to AIDS in the PRC,” synthesizes the arguments of Professors Li and Xia and recommends specific revisions to existing laws and rules. His main suggestions are:

- To officially reclassify AIDS (at present it is grouped along with typhoid, paratyphoid, diphtheria, rabies, anthrax, typhus, encephalitis, and other diseases communicable through ordinary human contact), and delete the requirement that AIDS patients “shall be isolated for treatment” in the Law of the PRC on the Prevention and Treatment of Infectious Diseases (1989).
- To amend the Decision of the Standing Committee of the NPC on the Prohibition of Narcotic Drugs (1990), which currently stipulates detention, fines, and compulsory re-education for drug users, with a requirement to “treat and educate” them, offering methadone replacement to those who fail to quit.
- To shift criminal responsibility for prostitution from sex workers to the organizers of commercial sex, and moral responsibility from sex workers to their clients. Sex workers, Professor Qiu recommends, should receive “education for prevention of AIDS and STDs and vocational training.”

while their clients should be subject to “compulsory education in law and morality.” Appropriate revisions should be made to the NPC Standing Committee Regulations of the PRC on Administrative Penalty for Public Security (1986) and the Decision of the Standing Committee of the NPC on the Strict Prohibition of Prostitution and Whoring (1991). Passages that link AIDS management to punitive campaigns against drugs and commercial sex should be deleted from more recent policy statements – eg, the State Council’s Opinions on Reinforcing the Prevention and Control of AIDS (1995), which states that “the prevention of AIDS is closely related to the prohibition against narcotic drugs and prostitution, to the purification of the social atmosphere and the construction of socialist spiritual civilisation,” and the Guiding Opinions for the Implementation of the Medium and Long Term Plan for AIDS Prevention and

Control (2001), which reiterates that “whoring, prostitution, drug trafficking and drug use must be vigorously cracked down upon.”

- To amend the Law of the PRC on Maternal and Infant Health Care (1995), deleting HIV from a list of “target infectious diseases” for which intending couples should be screened and treated before marriage.
- Extensive revision to the Regulations on the Monitoring and Control of AIDS (1988), deleting current requirements for compulsory HIV testing of long-term foreign residents in China and requirements of Chinese citizens returning from overseas, and creating confidentiality and privacy for HIV-positive people and AIDS patients. Article 2 currently cites “AIDS patients, ... persons infected with HIV, [and] suspected AIDS patients and people in close contact [with them]” as the “objects of monitoring and control.” This should be revised to make it clear that control efforts

“should point only to the disease, not the person.” Professor Qiu also favours the drafting of a new Law on the Prevention and Care of HIV/AIDS, with express commitments to prevent discrimination against HIV-positive people, to “defend human rights,” and to enhance the role of non-governmental organizations in prevention and care strategies.

Professors Qiu, Li, and Xia presented their findings to a June meeting hosted by UNDP in Beijing as part of an ongoing “Enabling Legislative Environment” project. Final versions of their research papers will be published later in 2002.

¹ UN Theme Group on HIV/AIDS in China. HIV/AIDS: China’s Titanic Peril. 2001 update of the AIDS situation and needs assessment report. Geneva: UNAIDS, 2002, at 36 (www.unaids.org/whatsnew/newadds/AIDSchina2001update.pdf).

² *Ibid* at 34.

³ This article was adapted, with permission, from N Young. Scholars call for AIDS rules based on respect for individual rights. *China Development Brief* 2002; 5(1), available via www.chinadevelopmentbrief.com/.

ILO Training for Industrial Court Judges

In this article Jane Hodges, Senior Labour Law Specialist, International Labour Office,¹ examines the role of the International Labour Organization in improving the response of the labour court system to the challenges of HIV/AIDS.

Labour court judges, and the whole labour court system, comprise a badly neglected part of labour administration. At the national level, continuing professional upgrading may exist only for the staff of civil and criminal courts, and specific courses on human rights and the

judicial system often target only specialized human rights bodies, such as equality commissions or race relations boards.

The ILO has a 20-year history of working with labour courts. It has provided a forum for exchanges on recent developments in labour law

and has implemented technical cooperation programs to improve day-to-day functioning of dispute-resolution institutions as well as the substantive quality of their work. This work has been carried out against the backdrop of ILO conventions ratified by member states and the fundamental principles and rights at work, including freedom of association and elimination of employment discrimination, child labour, and forced labour.²

Training for courts on the workplace implications of HIV/AIDS commenced only recently, with seminars in three subregions: Southern Africa (Harare, February 1999); the Caribbean (Port-of-Spain, October 1999); and East Africa (Kampala, April 2001). This training began in response to requests from ILO member states, where industrial tribunals and labour courts have started receiving cases – in some jurisdictions, a large number of cases – concerning employment aspects of HIV/AIDS. The requests also cover technical assistance in handling the increased caseload.

The demand for training also appears to result from the fact that more and more countries are revising their labour law frameworks to include perceived or actual HIV infection as a prohibited ground of discrimination in employment.³ ILO assistance in labour law reform has always included training for the institutions that are to enforce the revised laws. Added impetus for this training comes from the ILO's Code of Practice on HIV/AIDS in the World of Work, adopted in June 2001.⁴ The Code exhorts governments and competent authorities

to supply technical information and advice to employers and workers concerning the most effective way of complying with legislation and regulations applicable to HIV/AIDS and the world of work. They should strengthen enforcement structures and procedures, such as factory/labour inspectorates and *labour courts and tribunals*.⁵

High-quality workshops, seminars, courses, colloquia, and technical meetings for courts are conducted alongside the traditional training for employers, workers, and their organi-

zations on the right not to be discriminated against in employment on the basis of real or perceived HIV/AIDS status.

To support the courses, the ILO published a training manual which contains a chapter on HIV/AIDS discrimination in the world of work.⁶ The manual has also been used by the ILO's International Training Centre, Turin, in its course "International Labour Standards for Judges, Lawyers and Legal Educators."

In addition, for each training event the ILO contracts papers from national legal practitioners or law faculty staff, which draw on HIV/AIDS-related court cases from the particular region as a source of comparative labour law. Examples of good practice are shared, including trends in recent jurisprudence (eg, the "inherent requirements of the job" test for attempting to exclude HIV-positive applicants from the military).⁷ Where they exist, resource persons from national AIDS programs can be called upon to facilitate panels. During the seminars, numerous practical exercises are used, including a mock trial. Participants update their skills in writing decisions, and share information on evidential rules, disclosure and medical confidentiality rules, court proceedings, representational rights, and appeal processes.

ILO support to labour courts aims to contribute to a fuller understanding among staff of industrial tribunals – particularly judges and assessors – of the ILO standards and principles concerning equality in employment and occupation and how they can stop unfair employment practices with regard to HIV/AIDS. By providing up-to-date information and training – including examples of

protection and prevention laws, policies, and jurisprudence, and the most recent medical information – staff are better equipped to deal with issues that arise in HIV/AIDS. For further information, contact Jane Hodges (hodges@ilo.org).

¹ The International Labour Office is the Secretariat of the International Labour Organization (ILO) charged with implementing ILO decisions.

² These rights are listed in the 1998 Declaration on Fundamental Principles and Rights at Work, available at www.ilo.org/public/english/standards/decl/declaration/text. For more information about the Declaration and its follow-up, see the InFocus Programme on Promoting the Declaration at www.ilo.org/public/english/standards/decl/index.htm.

³ These frameworks are defined by the ILO to include labour codes; acts concerning employment rights, equality, disability, trade unions and employer organizations, industrial relations, child labour; labour courts, social security, and occupational safety and health; subsidiary regulatory instruments in the form of regulations, rules, and orders; and "soft law" such as codes of practice, disciplinary/conduct codes, and global compacts.

⁴ Geneva: International Labour Office, 2001. For the full text of the code, and more information about the implications of HIV/AIDS in the workplace, see the website of ILO/AIDS at www.ilo.org/public/english/protection/trav/aids.

⁵ Section 5.1(k), emphasis added.

⁶ *An Outline of Recent Equality Issues in Employment for Labour Court Judges and Assessors*. Geneva: International Labour Office, 1997. Available in English, Portuguese, and French.

⁷ For a discussion of recent approaches by courts in Namibia, South Africa, and Australia, see J Hodges. Policy and Legal Issues Concerning HIV/AIDS and the World of Work. Geneva: International Labour Office, 1999; updated 2002 (available via www.ilo.org/public/english/protection/trav/aids/intro) [site under reconstruction]. See also L Stoltz. HIV Testing of UN Peacekeeping Forces: Legal and Human Rights Issues. Background Paper for the UNAIDS Expert Panel on HIV Testing in UN Peacekeeping Operations. Montréal: Canadian HIV/AIDS Legal Network, 2001 (available via www.unaids.org/publications/documents/uniformservices).

International Forums

This section reports on the attention given to HIV/AIDS and health in international forums, including the appointment of a UN special rapporteur on the right to health.

HIV/AIDS and Health at the World Summit on Sustainable Development

The link between health and sustainable development was a central theme of the World Summit on Sustainable Development (WSSD), which took place in Johannesburg from 26 August to 4 September 2002. The Summit focused on implementing sustainable development by tackling environmental degradation and poverty. It underscored the importance of eradicating poverty in moving to ensure health gains for all people, and stressed the urgent need to address the underlying causes of ill health and their impact on development.

The WSSD concluded with the adoption of a Plan of Implementation calling for actions to be taken in a number of areas, including strengthening the capacity of health-care systems “to deliver basic health services to all, in an efficient, accessible and affordable manner aimed at preventing, controlling and treating diseases, and to reduce environmental health threats, in conformity with human rights and fundamental freedoms and consistent with national laws and cultural and religious values, taking into account the reports of relevant United Nations conferences and summits and of special sessions of the General Assembly.” With regard to HIV/AIDS, the Plan of Implementation reiterates the goals and targets contained in the UN General Assembly Declaration of Commitment of June 2001 and lists actions to be taken by

states in order to achieve these commitments. The full text of the Plan of Implementation, along with details of the Summit, may be found at www.johannesburgsummit.org.

UNAIDS sponsored a panel discussion at the WSSD on HIV/AIDS, human capacity, and sustainable development. The panel discussion considered the impact of AIDS on human development in key development sectors, including education, health, and food security. Panelists examined the experiences in countries where the epidemic has been prevented and subdued, and considered the elements of success to be drawn from these experiences. The discussions stressed the importance of ensuring the centrality of a rights-based approach that focuses on realizing the right to information, education, health, housing, and protection against all forms of discrimination, as well as the mainstreaming of HIV/AIDS responses into all development activities at the national level. A background paper prepared for the panel discussions, entitled HIV/AIDS, Human Resources, and Sustainable Development,¹ is available at www.unaids.org under “What’s New.”

African Regional Follow-up to the World Conference against Racism

The Durban Declaration and Programme of Action, which was adopted at the World Conference against Racism in 2001, sets out a detailed agenda for states and others

to take effective action against racism, racial discrimination, xenophobia, and related intolerance. A regional follow-up seminar of experts for the African region was held on 16-18 September 2002 in Nairobi, Kenya. The seminar was organized by the Office of the UN High Commissioner for Human Rights, in cooperation with the United Nations Office at Nairobi. Participants included representatives from the UN system, African national human rights institutions, academia, and African civil society.

The three-day meeting brought the experts and about a hundred observers from African states and other organizations together to discuss topics such as development and poverty, the administration of justice, health and HIV/AIDS, national action plans against racism, and the gender dimensions of racial discrimination. The seminar concluded with a series of recommendations to African states on how they might practically move forward to implement the provisions of the Durban Programme of Action.

The recommendations relating to health included reference to legislative and policy frameworks that respect, protect, and fulfil the fundamental human right of all persons to the highest attainable standard of health. The experts also recommended that states develop and implement, in consultation with non-governmental organizations and in particular with people with HIV/AIDS, national plans to realize progressively universal access to comprehensive treatment, care, and support for all people living with

HIV/AIDS, as well as indicators and benchmarks to monitor progress.

The complete recommendations of the Seminar of Experts for the African Region are available on the website of the Office of the High Commissioner for Human Rights at www.unhchr.ch/html/racism/index.htm.

UN Appoints a Special Rapporteur on the Right to Health

In early 2002, the UN Commission on Human Rights adopted a resolution creating a new mandate to focus on health issues from a human rights perspective. The resolution notes

that, for millions of people around the world, the full enjoyment of the right to health is a distant goal that is becoming increasingly remote in many cases – in particular for those living in poverty. It recognizes a need for states, in cooperation with international organizations and civil society, to create favourable conditions at all levels to ensure the full and effective enjoyment of the right to health. The resolution mandates, for a three-year term, the appointment of a special rapporteur.

The Commission nominated Paul Hunt (New Zealand) as special rapporteur in August 2002. His mandate will include gathering and exchange-

ing information, reporting on the status throughout the world of the realization of the right to health, and making recommendations on appropriate measures to promote and protect the realization of the right health. The special rapporteur will present his first report to the Commission at its 59th session in March 2003. The full text of the resolution on the right to health (E/CN.4/RES/2002/31) is available on the website of the Office of the High Commissioner for Human Rights via www.unhchr.ch.

¹ Geneva: Joint United Nations Programme on HIV/AIDS, 2002.

African Regional Meeting on HIV/AIDS and Human Rights

A meeting of countries in the Southern African Development Community (SADC) leads to the establishment of a regional alliance of organizations working on HIV/AIDS and human rights.

On 25-26 October 2002, the AIDS Law Unit of the Legal Assistance Centre of Namibia and the AIDS Law Project of South Africa co-hosted a meeting in Windhoek, Namibia, of organizations working on HIV/AIDS and human rights in the SADC region.

The purpose of the meeting was to revisit the importance of a rights-based response to HIV/AIDS; to share the experiences of organizations working on these issues in Africa; and to explore the establishment of a network of organizations working on HIV/AIDS and human rights in Africa with a view to providing an ongoing forum for the sharing of ideas, experi-

ences, materials, and expertise on human rights, law, and policy in the context of HIV/AIDS.

The meeting was attended by 60 participants, representing 10 SADC countries, namely South Africa, Botswana, Zambia, Swaziland, Tanzania, Zimbabwe, Malawi, Angola, Mozambique, and Namibia. Emma Tuaepepa, Director of Lironga Eparu, the Namibian national association of people with HIV/AIDS, opened the meeting, and a keynote address was delivered by Mr Justice Edwin Cameron of South Africa.

Participants shared information on the work currently being undertaken on HIV/AIDS and human rights in the

various SADC countries represented at the meeting, and identified common needs. Central to these was the need for sharing of expertise, materials, and experiences in the region.

To meet these needs, the participants resolved to establish a regional alliance of organizations working on HIV/AIDS and human rights. The functions of this alliance will be to facilitate sharing of information, materials, and expertise between members, to act as a regional alert network to respond to human rights infringements in the region, to organize and facilitate training opportunities on HIV/AIDS and human rights for members, to disseminate information on regional developments on HIV/AIDS and human rights, and to organize annual meetings on HIV/AIDS and human rights in the

region. The alliance will be coordinated by a secretariat hosted by the AIDS Law Unit of the Legal Assistance Centre of Namibia. An advisory board consisting of representatives from the AIDS Law Project (South Africa), the AIDS Law Unit (Namibia), Women and Law in Southern Africa (Swaziland), the Southern Africa AIDS

Information Dissemination Service (Zimbabwe), the Zambian AIDS Law Research and Advocacy Network (Zambia), Lironga Eparu (Namibia), and Programa de Direitos Humanos (Angola), will be established.

The meeting was made possible by financial support from Family Health International, USAID, Ibis,

the Voluntary Service Overseas Regional AIDS Initiative of Southern Africa (VSO RAISA), and the Southern Africa Human Rights NGO Network (SAHRINGON). For further information on this meeting and the regional alliance, please contact Michaela Figueira at the AIDS Law Unit, Legal Assistance Centre, Namibia (mfigueira@lac.org.na).

Nigeria Health Rights Group Provides Legal Support

Nigerian organization takes action on the rights of people with HIV/AIDS in clinical trials

The Center for the Right to Health, Lagos, continues to provide legal support for people with HIV/AIDS in Nigeria. This is done through legal counselling, drafting of documents, mediation, and litigation. Each week about ten people with HIV/AIDS visit the Center for various forms of legal assistance. The Center has intervened in the case of an elderly man who was treated unethically. In another action in early 2002, the Center petitioned to a regulatory body outlining human rights violations occasioned by the attitudes of health workers. The body

took disciplinary action against the health workers, and the patient was modestly compensated.

In August 2002, the Center completed a paper entitled "Drug Trials: Documenting the Experience of People Living with HIV/AIDS in Nigeria." The Center decided to prepare this paper following complaints about unethical practices in a trial organized by the federal government in 2001. The research revealed that informed consent of participants was not properly obtained, care and treatment were not provided for partici-

pants during the trial, and their human dignity was not respected. Subsequently, the Center organized a workshop on drug trials for about thirty people with HIV/AIDS. Experts presented papers on the meaning of clinical trials, ethical principles in clinical trials, and the rights of trial subjects during trials.

In August 2002, the Center published a pamphlet entitled *Your Rights In Clinical Trials*, written to educate the public and in particular people with HIV/AIDS on their rights in clinical trials. The Center also publishes *Touch*, a quarterly journal of legal issues on HIV/AIDS, human rights, and reproductive health. For further information contact Durojaye Ebenezer Tope (crhuids@yahoo.com).

Legislative Initiatives in the Asia Pacific Region

This section reports on legislative developments in Australia, Papua New Guinea, and Cambodia.

Australian Legislative Audit

In 2002, the AIDS Trust of Australia funded a legislative audit to measure Australia's compliance with the

International Guidelines on HIV/AIDS and Human Rights. The project will apply the Guidelines in

each of Australia's nine legal jurisdictions (six states, two territories, and the federal jurisdiction), and is being conducted in conjunction with the Australian Federation of AIDS Organisations and local community HIV/AIDS organizations in each jurisdiction. Representatives of law and health ministries in each jurisdiction also participate in the review, which aims to foster participation and

reflection by all parties on how to improve the Australian legal environment to enhance the response to the epidemic. The final report of the project is due early in 2004. For further information, contact Helen Watchirs, Regulatory Institutions Network, Australian National University (watchirs@coombs.anu.edu.au).

Papua New Guinea Approves Draft HIV/AIDS Legislation

The National AIDS Council of Papua New Guinea has approved a draft HIV/AIDS Management and Prevention Bill, which it hopes will go before the newly elected Papua New Guinea parliament in late 2002. The main thrust of the legislation is the protection and promotion of human rights in the context of the epidemic, with a focus on combating stigma and discrimination, and mandatory HIV screening. Papua New Guinea has an elaborate system of human rights entrenched in its constitution, which the courts are frequently called upon to uphold, and the draft Bill relies on these rights being implemented. The Bill also draws on the International Guidelines on HIV/AIDS and Human Rights and the International Labour Organization's Code of Practice on HIV/AIDS and the World of Work.

Features of the Bill include the prohibition of discrimination against people living with or suspected of having HIV/AIDS, their families, friends, and associates, as well as against people associated with groups thought to be at high risk of HIV infection. HIV screening is pro-

hibited in most circumstances, and the Bill provides for a legal right of access to the means of HIV prevention, including condoms and HIV/AIDS-awareness materials, which are not subject to censorship or obscenity laws. There is a legal obligation of confidentiality concerning HIV-related information, and almost all HIV testing must be done with voluntary informed consent and pre- and post-test counselling. For further information on the Bill, contact Christine Stewart, Policy and Legal Advisor, Papua New Guinea National HIV/AIDS Support Project (cstewart@nhasp.nacs.org.pg).

Cambodia Legislates on HIV Prevention

Cambodia's National Assembly has passed comprehensive legislation on HIV prevention and control. The Law on the Prevention and Control of HIV/AIDS received royal assent in July 2002, and provides for national HIV/AIDS awareness campaigns, epidemiological monitoring, and free primary health care for people with HIV/AIDS. The law requires the protection of confidentiality of HIV/AIDS information, with fines and imprisonment for up to six months for breaches. All forms of discrimination against people with HIV/AIDS are prohibited, as is discrimination against families of people with HIV/AIDS and people thought to be HIV-positive. In almost all circumstances HIV testing must be voluntary, anonymous, and subject to written consent and to pre- and post-test counselling. HIV screening is prohibited in connection with employment, education, free-

dom of residence and movement, and access to medical and other services.

The legislation, which is based on the Philippines' AIDS Prevention and Control Act 1998, charges Cambodia's National AIDS Authority with responsibility for developing HIV-education programs in the workplace, establishing and monitoring infection control standards, regulating advertising standards for HIV-prevention and treatment products, and collecting resources "both inside and outside the country" for Cambodia's response to the epidemic. The National AIDS Authority is also responsible for ensuring standards in HIV testing centres and for collecting epidemiological data in coded (ie, non-identifying) form.

Implementation of this ambitious program of activities is to be the subject of further (as yet unwritten) guidelines, but non-governmental organizations such as the USAID-funded POLICY Project and the Cambodian People Living with HIV/AIDS Network (CPN+) have started advocacy initiatives based on the new legislation. In September 2002, the POLICY Project and the Australian Federation of AIDS Organisations conducted a seminar in Phnom Penh on aspects of the legislation for HIV/AIDS and human rights organizations. CPN+ will draft a Bill of Rights for people with HIV/AIDS drawing on the provisions of the new law.

For further information, contact the POLICY Project in Phnom Penh, Cambodia (m.coleman@bigpond.com.kh) or Chris Ward (cward@afao.org.au).

HIV/AIDS Discrimination in the Asia Pacific Region

Six-Country Study of HIV/AIDS Stigma and Discrimination

A research project funded by the Ford Foundation is using a UNAIDS protocol¹ to examine institutional forms of HIV/AIDS-related stigma and discrimination in China, India, Indonesia, Philippines, Thailand, and Vietnam.² The protocol focuses on three sources of possible discrimination: legislation, written and unwritten policies, and practice. These sources of possible discrimination are examined across 10 key sectors of public life, including health care, law, education, and social services.

Each country team has a coordinator and a technical advisor, combining expertise in research, advocacy, and the lived experience of HIV/AIDS-related discrimination. Research teams in each country gather documentation and interview key informants, including people working in the relevant sectors and people living with or affected by HIV/AIDS.

Half the participating countries are expected to have conducted national workshops on their research teams' findings by December 2002, with the other half expecting this to occur around April 2003. For further infor-

mation, contact Kit Yee Chan (kityc@deakin.edu.au).

Report on HIV/AIDS Discrimination in Australia

People with HIV in Australia continue to experience significant discrimination, according to a report by the Australian Research Centre in Sex, Health and Society.

The report, *HIV Futures 3: Positive Australians on Services, Health and Well-Being*,³ found that issues of discrimination remain central to the life of many HIV-positive people, whether because of discrimination or through anticipation of the possibility of discrimination.

Of the 898 people responding to the *HIV Futures* survey, 11.1 percent indicated they had received less favourable treatment in relation to accommodation. More people living in public housing said they had experienced discrimination (24.6 percent) than people living in private rental accommodation (9.6 percent).⁴

37.7 percent of respondents had experienced discrimination at a medical service as a result of having HIV. When asked what form this discrimination took, respondents most com-

monly specified confidentiality problems and avoidance.⁵

In relation to disclosure of their HIV status, 52 percent of respondents said that at some point their HIV status had been disclosed without their permission, and 29.7 percent said that this had happened in the last two years. According to respondents, people most likely to disclose a person's HIV status without their permission were friends or work colleagues. The authors observed that these people are most likely to be aware of the respondent's HIV status, and expressed concern that 18.4 percent of respondents nominated a worker in a health-care setting as the source of unwanted disclosure.⁶

The authors plan to publish a more detailed paper on the survey's findings in relation to discrimination.

¹ 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).

² D Reidpath, KL Chan. HIV/AIDS-related discrimination in the Asia Pacific. *HIV Australia* 2002; 291: 32.

³ 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).

⁴ Ibid at 109.

⁵ Ibid at 109-110.

⁶ Ibid at 57-58.

Police Abuses Hinder HIV Prevention in Cambodia and India

Reports from Cambodia and India show how human rights violations by police undermine efforts to prevent the spread of HIV.

Human Rights Violations of Sex Workers in Cambodia

A report by the Cambodian Women's Development Association (CWDA) and the Cambodian Prostitutes Union has found that women working in the sex industry in the Toul Kork district in Phnom Penh are continuously subjected to human rights violations by police, including illegal arrests, beatings, extortion, and rape. The report states that the lack of respect for the human rights of Cambodian sex workers is fuelling the HIV epidemic in that country, making it impossible for women sex workers to refuse clients or protect themselves against HIV and sexually transmitted infections.

Cambodian law prohibits the ownership and operation of brothels and the trafficking of people for prostitution, but sex work itself is not illegal. However, the CWDA report states that it is sex workers rather than brothel owners and operators and their clients who are systematically targeted and incarcerated.

Of the sex workers surveyed, 72 percent said they had experienced a human rights violation by police.

Violations included arbitrary arrest, denial of the right to work, beating with sticks and guns, rape, forced labour, and extortion. All sex workers reported the belief that the stigma associated with sex work in Cambodian society meant that sex workers were denied the protections to which they are entitled under Cambodian law. Many of the sex workers stated that local authorities and the Cambodian government need to take action to stop the exploitation of sex workers.

The Cambodian Women's Development Association has called for urgent action, including training for police officers that focuses on the human rights of women, and criminal proceedings against police who misuse their authority to violate sex workers' human rights. Copies of the report are available from the Cambodian Women's Development Agency (cwda@bigpond.com.kh).

Harassment of HIV/AIDS Workers in India

Human Rights Watch has found that abuse and harassment of HIV/AIDS workers by police in India is undermining efforts to contain the spread of

HIV in that country. In a report released at the XIV International AIDS Conference,¹ Human Rights Watch found that abuses of outreach workers who work with sex workers and men who have sex with men are frequent and widespread. In effect, one branch of government – the public health service – relies on the non-governmental sector to provide condoms and information to people at high risk, while another branch of government – law enforcement – abuses those who provide these services.

The report makes a range of recommendations, including the repeal of section 377 of the Indian Penal Code, which criminalizes sex between men and is frequently used as justification for harassment of HIV/AIDS educators working with men who have sex with men. The report also calls for a parliamentary inquiry into human rights violations against HIV/AIDS outreach workers with a view to strengthening legal protections of human rights.

¹ J Csete. Epidemic of abuse: police harassment of HIV/AIDS outreach workers in India. *Human Rights Watch*

HIV Testing: Progress in Hungary, Problems in Russia

Voluntary anonymous HIV testing is about to become the norm in Hungary. Mandatory HIV testing, however, is widespread in Russia, contrary to the federal law on HIV prevention.

Hungary: Saved by the Bell – Voluntary and Anonymous Testing

The new Hungarian legislation on HIV/AIDS follows from a June 2002 decision of the constitutional court. The court invalidated the ministerial decree of 1988, holding that too many fundamental rights were involved for this level of regulation to be adequate, and gave the parliament until 31 December 2002 to fill this legislative vacuum.

Given the time constraints and the fact that the court had not found the decree unconstitutional on its merits (when it invalidates a text because of a formal defect, it never examines the legal arguments on their merits), the government chose the easy way out and merely repeated and integrated the provisions of the decree into the Health Act, without taking their content into account, contrary to the recommendations and directives of the World Health Organization and the United Nations Joint Programme on HIV/AIDS.

These provisions established a *semi-anonymous testing* system in which there is anonymity only until the first positive test (providing one's personal data being the precondition for access to the verification test), prescribed *partner notification*, and made testing *compulsory* for some groups in particular: sexual partners of seropositive people, people in close contact with seropositive peo-

ple who could be infected, prisoners, and injection drug users.

This draft amendment, which did not differentiate at all between HIV/AIDS and infectious diseases in general, raised a barrage of protests from non-governmental organizations, doctors involved in treating people infected with HIV, and the mediator responsible for data protection. With the assistance of the media, the Ministry of Health was forced to reformulate its proposal, this time in collaboration with the mediator, whom it had initially “forgotten” to consult.

In spite of some inconsistencies and defects, the new version of the bill is rather encouraging: it makes *voluntary and anonymous testing the general rule*. Compulsory testing, however, still applies to too many people – other than blood and organ donors, the test may be made compulsory, if there is a risk of transmission, to those suspected or accused of sexual offences, drug use, or other offences that cause bodily harm, and where the judge deems it necessary to establish whether there has been infection. The amendment also introduces compulsory testing in professions where there is a risk of infection. In this respect, the law is unfortunately still influenced by traditional reflex reactions that offer only the illusion of security. Limitations of human rights do not always fully meet the criteria of necessity and proportionality.

For more information, contact Eszter Csernus, Hungarian Civil Liberties Union (tarsasag@elender.hu).

Russia: Widespread Testing Contravenes International and National Law

In September 2002 the Head of the Sanitary Department of the Russian Ministry of Health noted that widespread mandatory testing contravenes international and national legislation.¹ He gave as an example the Primorsky region, where every Russian citizen who wished to leave the country for more than three days has to “pass” an HIV test. He also noted cases of discrimination against people with HIV/AIDS among medical professionals. This was reportedly due to their lack of adequate knowledge about HIV transmission and resulted in people with HIV/AIDS not getting the required medical assistance. The 1995 Russian federal law on HIV prevention guarantees voluntary, consensual HIV testing and protection from discrimination on the grounds of one's HIV status. The region covered by the countries of the former Soviet Union is currently experiencing the fastest-growing HIV epidemic in the world. Some estimate that there may be as many as one million Russians infected,² while the official number of registered cases is around 195,000. For further information, contact Anna Alexandrova (AnnaAlexandrova@aol.com).

¹ Decree of the Head Sanitary Doctor of the Russian Federation # 28, On the Strengthening of HIV Prevention Activities, 9 September 2002, available in Russian at www.minzdrav-rf.ru.

² One million Russians could die of AIDS by 2012. Interfax, 20 February 2002.

El Salvador: Legislature Removes Law Allowing Pre-employment HIV Testing

After a year of criticism, on 11 October 2002 the Legislative Assembly of El Salvador eliminated provisions in the nation's Law on the Prevention and Control of the Infection caused by the Human Immunodeficiency Virus that authorized potential employers to require

pre-employment HIV testing of job applicants.¹ The new statute, dealing with various legal questions related to HIV/AIDS, was enacted in October 2001. Article 16(d) introduced the pre-employment testing provision, and activists had filed a constitutional challenge to this provision in the

Supreme Court.² Many of the remaining articles in the Law raise human rights concerns as well,³ and will require further advocacy by human rights activists.

¹ El Salvador: Derogan artículo de ley que discrimina a PVS's, *Boletines Informativos: Acceso Centroamérica*, 9 November 2002 (www.aguabuena.org/boletines/noviembre092002.html).

² R Elliott: El Salvador: activists challenge law allowing pre-employment HIV testing, *Canadian HIV/AIDS Law & Policy Review* 2002; 7(1): 56-58.

³ El Salvador, *supra*, note 1.

GLOBAL ACCESS TO TREATMENT

This section of the *Review* addresses issues related to improving access to adequate and affordable care, treatment, and support everywhere. It reports on major decisions by courts in South Africa and Thailand; a revised international guideline on access to prevention, treatment, care and support; actions by the UN Commission on Human Rights, the World Health Organization, and the Global Fund to Fight AIDS, Tuberculosis and Malaria in support of increased access to treatment; an important UK report on the impact of intellectual property laws on developing countries; legislative and regulatory decisions in China and Kenya; and other developments. The articles are compiled by Richard Elliott, Director, Policy & Research, Canadian HIV/AIDS Legal Network (on leave of absence until 1 September 2003). He can be reached at relliott@aidslaw.ca.

South Africa: Highest Court Orders Government to Provide Antiretrovirals to Prevent Mother-to-Child Transmission

On 5 July 2002, South African treatment activists won a significant victory when the Constitutional Court ordered the South African government to make the antiretroviral drug nevirapine available in public hospitals and clinics for the purposes of preventing mother-to-child transmission of HIV. The Court also ruled the government has a constitutional obligation to implement a program to realize the right of pregnant women and their newborn children to access health services to prevent transmission.¹

The South African government had chosen not to roll out a national pro-

gram to reduce the risk of transmission of HIV between mother and

child. Instead it had identified two sites per province that were to participate in a study that would test various aspects of the program. It also declined to make nevirapine available to sites that did not fall within the study and prohibited hospitals outside the pilot sites from prescribing and administering nevirapine to mothers with HIV.

After four years of lobbying, advocacy, and public mobilization, the Treatment Action Campaign (TAC) and other applicants brought their application in the High Court in Pretoria in August 2001, seeking to

compel the government to ensure access to nevirapine for all HIV-positive pregnant women and their newborn children. In December 2001, the High Court ruled in TAC's favour.² The government appealed, and the Constitutional Court's judgment was handed down in early July 2002, on the eve of the XIV International Conference on AIDS in Barcelona.

The judgment was delivered unanimously by the eleven judges.

Unusually, the judgment was delivered unanimously by the eleven judges rather than ascribed to any particular justice, a mark of the seriousness with which the highest court in South Africa viewed this case. The judgment concentrates in particular on two constitutional rights of South Africans: the right to access health-care services, including reproductive health care (section 27), and children's right to basic health-care services (section 28).

Section 27: Right to Access Health-Care Services

The court found that there was no need to consider whether socio-economic rights are enforceable, as "clearly they are."³ Therefore, the question before the court was whether TAC had demonstrated that the program adopted by the government to "provide access to health-care services for HIV-positive mothers and their newborn babies fall[s] short of its obligations under the Constitution."⁴

The court reduced the issues between TAC and the government to two key issues – namely, whether it

was reasonable for government to restrict nevirapine to the pilot sites, and whether government had in fact a "comprehensive policy for the prevention of mother-to-child transmission."⁵

The government advanced four reasons for its refusal to allow nevirapine to be prescribed outside the pilot sites: (1) concerns about the *efficacy* of nevirapine where the so-called comprehensive package of care provided at the pilot sites was not available; (2) the question whether the provision of the single dose of nevirapine to mother and child would lead to *resistance* to nevirapine and other antiretrovirals at a later stage; (3) the *safety* of the drug itself; and (4) whether *capacity* existed in the public sector to provide the full package of care.

The court dealt carefully and comprehensively with each of these issues. Dealing first with the question of *efficacy*, the court found unequivocally that it was clear "from the evidence that the provision of nevirapine will save the lives of a significant number of infants even if it is administered without the full package and support services that are available at the research and training sites."⁶ The court went so far as to state that even where mothers did not have access to breast milk substitutes (which are provided at the pilot sites) or elected to breastfeed, the benefits of nevirapine are not lost.⁷

The court also rejected the argument concerning drug *resistance*, saying that this risk was well worth running, given the alternative of suffering and death because of HIV infection. On the evidence, the court also found that concerns about the *safety* of the drug were no more than hypothetical, with the drug recommended without qualification by the World Health Organization for the

purpose of preventing mother-to-child transmission and registered for this purpose by the South African Medicines Control Council.

With respect to the question of capacity, the court acknowledged that limited resources and a lack of adequately trained personnel were relevant to government's ability to make a "full package" of care available throughout the public sector. However, this was not relevant to the question of whether nevirapine should be used at public hospitals and clinics outside the research sites, where the necessary testing and counselling facilities do exist.

The court then considered whether the policy of confining nevirapine to the pilot sites was reasonable. It found that the policy

fails to address the needs of mothers and their newborn children who do not have access to these sites. It fails to distinguish between the evaluation of programmes for reducing mother-to-child transmission and the need to provide access to health care services required by those who do not have access to the sites.⁸

The court examined the decision not to provide nevirapine outside the pilot sites against the criteria developed in its earlier *Grootboom* decision,⁹ and found that the policy failed to deal with the needs of those who were most in need, was "an inflexible one,"¹⁰ and was in breach of section 27(2) of the Constitution.

The court then examined whether a comprehensive plan existed to combat mother-to-child transmission of HIV. It found that these issues were closely related to the policy to prohibit the prescription of nevirapine outside the pilot sites. It carefully examined all the evidence adduced by both the applicants and the respondents, and

concluded that the full package of treatment for the prevention of mother-to-child transmission provided at all pilot sites included: counselling and testing; nevirapine, where medically indicated; the provision of formula feed as a substitute for breastfeeding; and aftercare, including the provision of vitamins and antibiotics and monitoring of the progress of the children. At all public hospitals other than the pilot sites, nevirapine would not be available. However, the court found that evidence showed that many public facilities already had programs in place to provide testing and counselling, including counselling on feeding options. Some of these facilities also provided formula feed, although many did not.

The court found that the program, such as it was, did not meet the constitutional standard, as it again failed to include “those who could be reasonably included where such treatment is medically indicated to combat mother-to-child transmission of HIV.”¹¹

The government had argued vehemently that the court had no power to make an order that would have the effect of requiring it to pursue a particular policy. To do so would effectively undermine the doctrine of separation of powers, a fundamental concern of a constitutional democracy. In dealing with this argument, the court found that “although there are no bright lines that separate the roles of the legislature, the executive and the courts from one another, there are certain matters that are pre-eminently

within the domain of one or other of the arms of government and not the others.”¹² However, this did not preclude the court from making a decision that would have an impact on policy.

Section 28: Children’s Right to Basic Health-Care Services

Although the court did not deal with the rights of children in much detail in the judgment, there was something of a retreat from the position advanced in the *Grootboom* decision, where the court had ruled that the obligation to provide children rested primarily on their parents and not on the state. In this case, the court found that the state does have an obligation to children being cared for by family, but left the question open as to the exact nature and extent of the obligation.

The Court’s Order and Subsequent Developments

The court ordered the government to immediately remove all restrictions on the provision of nevirapine in hospitals that fell outside the pilot sites and to devise a comprehensive program to reduce the risk of mother-to-child transmission of HIV.

Treatment activists have hoped this Constitutional Court decision proves to be the final judgment in this matter between the national Minister of Health and the Treatment Action Campaign, with no further litigation needed on this front to secure at least this form of HIV/AIDS treat-

ment. However, although certain provinces have significantly increased access to nevirapine, many have not. Despite the legal victory, many women are unable to take steps to ensure that their children are protected from HIV infection and many children continue to be infected. On 15 October 2002, TAC met with the Deputy President to discuss the development and implementation of a national plan for prevention of mother-to-child transmission, pursuant to the court order.

– Liesl Gernholtz

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¹ *Minister of Health and others v Treatment Action Campaign and others*, Constitutional Court of South Africa, Case No. CCT 08/02 (available online at www.tac.org.za).

² Case No 21182/2001, 14 December 2001, High Court of South Africa (Transvaal Provincial Division), Botha J. The court papers and the judgment are available online at www.tac.org.za, and a summary can be found at: L Gernholtz. Preventing mother-to-child transmission: landmark decision by South African court. *Canadian HIV/AIDS Policy & Law Review* 2002; 6(3): 1, 20-24.

³ *Minister of Health v TAC* (Constitutional Court), supra, note 1 at para 25.

⁴ *Ibid.*

⁵ *Ibid* at para 47.

⁶ *Ibid* at para 57.

⁷ *Ibid* at para 58.

⁸ *Ibid* at para 67.

⁹ *Government of the Republic of South Africa and others v Grootboom and others*, 2001 (1) SA 46 CC; 2000 (11) BCLR 1169 (CC). The *Grootboom* case dealt with the issue of the government’s positive obligation to make reasonable provision within its available resources for realizing the right to have access to housing.

¹⁰ *Minister of Health v TAC*, supra, note 1 at para 80.

¹¹ *Ibid* at para 125.

¹² *Ibid* at para 98.

Update to International Guidelines on HIV/AIDS and Human Rights

On 10 September 2002, the Office of the UN High Commissioner for Human Rights (OHCHR) and the Joint UN Programme on HIV/AIDS (UNAIDS) released a revised international guideline on “Access to prevention, treatment, care and support.” The update to Guideline 6 of HIV/AIDS and Human Rights: International Guidelines reflects significant therapeutic, political, and legal developments in this area since the 12 guidelines were originally published in 1998. The new Guideline 6 significantly expands the guidance given to governments on what international human rights norms require of them in relation to HIV/AIDS prevention, treatment, care, and support.

Background

In 1995, the UN Secretary-General recommended to the UN Commission on Human Rights the development of guidelines outlining to governments “how human rights standards apply in the area of HIV/AIDS” and identifying “concrete and specific measures, both in terms of legislation and practice, that should be undertaken” to protect and promote respect for human rights in the context of HIV/AIDS.¹ The Commission agreed.² In 1996, UNAIDS and the OHCHR held the Second International Consultation on HIV/AIDS and Human Rights, bringing together a group of experts who drafted 12 guidelines for state action as well as recommendations for their implementation. They also produced a detailed discussion of how international human rights obligations apply to issues raised by HIV/AIDS. These materials were released by UNAIDS and the OHCHR in 1998. The Commission on Human Rights has urged states to ensure their laws, policies, and practices comply with the Guidelines and to report on the steps

they have taken to promote and implement them.³

Since the Guidelines were first released, there have been many developments related to access to HIV/AIDS treatment, care, and support. Some key developments include:

- The UN Commission on Human Rights has adopted resolutions confirming that access to HIV/AIDS medication is a key component of the human right to the highest attainable standard of health.⁴
- The UN Committee on Economic, Social and Cultural Rights, which monitors states’ compliance with the International Covenant on Economic, Social and Cultural Rights, has issued a “General Comment” on the right to health that makes it clear this includes access to treatment and HIV-related education.⁵
- The World Trade Organization has issued a Ministerial Declaration on its intellectual property agreement and public health.⁶
- The World Health Assembly has adopted resolutions on HIV/AIDS generally and the issue of access

to HIV/AIDS medicines specifically.⁷

- The International Labour Organization has issued a *Code of Practice on HIV/AIDS and the World of Work* that includes some guidance on care and support of workers infected and affected by HIV/AIDS.⁸
- Cases have been successfully brought before some regional human rights commissions and courts, as well as domestic courts in some countries, to compel government action to ensure access to antiretroviral and other medicines for either therapeutic treatment of people living with HIV/AIDS or to prevent mother-to-child transmission of HIV.⁹

In light of these and other developments, UNAIDS and the OHCHR decided to convene the Third International Consultation on HIV/AIDS and Human Rights in order to update Guideline 6. The consultation, held in July 2002, reviewed advances in HIV/AIDS-related treatment, the global disparity in access to treatment, and political and legal developments, and produced an updated draft text for a new Guideline. A background research paper was prepared as a basis for discussion, and a summary report of the meeting was prepared following the consultation.

Revised Guideline 6

The expert consultation agreed that guidance to states in this area should be based on the following key premises:

- access to HIV/AIDS-related treatment is fundamental to realizing the right to health;

- prevention, treatment, care, and support are a continuum;
- access to medication is one element of comprehensive treatment, care, and support;
- ensuring sustainable access to medication requires action on numerous fronts; and
- international cooperation is vital in realizing equitable access to treatment, care, and support to all in need.

The original Guideline 6 advised that

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

Five accompanying recommendations addressed the use of mass media to provide information about HIV/AIDS; regulations to ensure the quality and availability of HIV testing and counselling; legal quality control of condoms and access to these and other preventive measures such as clean needles; the revision of duties, customs laws, and value-added taxes to maximize access to safe and effective medication at an affordable price; and the importance of consumer protection laws to prevent fraudulent claims regarding drugs, vaccines, and medical devices.

The revised Guideline adds to this, expressly indicating that:

States should also take measures necessary to ensure for all persons, on a sustained and equal basis, the availability and accessibility of quality goods, services and information for HIV/AIDS prevention, treatment, care and support, including antiretroviral and other safe and effective med-

icines, diagnostics and related technologies for preventive, curative and palliative care of HIV/AIDS and related opportunistic infections and conditions.

States should take such measures at both the domestic and international levels, with particular attention to vulnerable individuals and populations.

The recommendations accompanying the revised Guideline have now been expanded to 26, incorporating the existing ones and adding new recommendations, such as the following.

- States should develop and implement national plans to progressively realize access to comprehensive treatment, care, and support, in consultation with non-governmental organizations and ensuring the active participation of people living with HIV/AIDS and vulnerable groups.
- States have an immediate obligation to take steps toward realizing access for all to HIV/AIDS prevention, treatment, care, and support, and this requires, among other things, setting benchmarks and targets for measuring progress.
- States should ensure their laws, policies, programs, and practices do not exclude, stigmatize, or discriminate against people living with HIV/AIDS with respect to access to health-care goods, services, and information.
- States should ensure domestic law provides for prompt and effective remedies in cases in which a person is denied or not provided access to treatment, care, and support.
- States should increase funds allo-

cated to the public sector for researching, developing, and promoting therapies and technologies for HIV/AIDS prevention, treatment, care, and support, and should encourage the private sector to undertake such research and development and make the resulting options widely and promptly available at affordable prices.

- States should increase national budget allocations for measures promoting secure and sustainable access to affordable prevention, treatment, care and support at both the domestic and international levels. This includes making contributions, in proportion to their resources, to mechanisms such as the Global Fund to Fight AIDS, Tuberculosis and Malaria. Furthermore, developed countries should meet international targets for official development assistance to which they have agreed.
- Creditor countries and international financing institutions should implement debt relief for developing countries more quickly and extensively, and developing countries should use resources thus freed up in ways that fully take into account their obligations to respect, protect, and fulfil rights related to health.
- States should ensure that, in international forums and negotiations, they take due account of international norms, principles, and standards relating to human rights and avoid taking measures that undermine access to HIV/AIDS prevention, treatment, care, and support, either domestically or in other countries. This includes ensuring that the interpretation and implementation of international agreements, such as

those on trade and investment, do not impede efforts to fully realize access to HIV/AIDS prevention, treatment, care, and support.

In releasing the updated Guideline 6, Mary Robinson, the UN High Commissioner for Human Rights, reminded governments that:

Access to HIV/AIDS treatment is key to realizing the fundamental human right to health. Under international human rights law, states have an obligation to take positive legislative, budgetary and administrative measures that progressively advance the right to the highest attainable standard of health. This commitment should be matched by resources, including from donors and the international community.¹⁰

Dr. Peter Piot, UNAIDS Executive Director, highlighted that:

With the advent of life-prolonging HIV treatment, and price barriers falling, access to treatment is now at the heart of realizing the human rights of people living with HIV/AIDS. The new Guideline 6 will help governments and civil society focus on the need to scale up access to prevention and treatment. Today's unequal and limited

access to treatment is unacceptable, with less than 5% of people in the developing world who need HIV medicines having access to them.¹¹

It will now be up to civil society organizations, as well as UN bodies such as UNAIDS and the OHCHR, to promote the revised International Guidelines and encourage states to follow the recommendations. Further reports from the UN Secretary-General to the UN Commission on Human Rights provide one mechanism for this, and both UNAIDS and the OHCHR should promote the revised Guidelines in various UN and regional forums, for example, human rights committees, commissions, courts, and other relevant conferences and meetings. Treatment activists and civil society organizations can also make use of the revised Guideline 6 in their advocacy in such international forums and directly with their national governments.

— Richard Elliott

Both the original HIV/AIDS and Human Rights: International Guidelines and the Revised Guideline 6 can be found on the websites of UNAIDS (www.unaids.org) and the OHCHR (www.unhchr.ch). Reports of the UN Secretary General, resolutions of

the UN Commission on Human Rights, and materials from UN committees dealing with human rights can also be found via the OHCHR website. International Labour Organization materials can be found on its website (www.ilo.org). World Trade Organization materials can be found on its website (www.wto.org).

¹ Report of the UN Secretary General, UN Doc. E/CN.4/1995/45, para. 135.

² Resolution 1996/43.

³ Resolutions 1997/33, 1999/49, 2001/51.

⁴ Resolutions 2001/33, 2002/32.

⁵ UN Committee on Economic, Social and Cultural Rights. General Comment No 14: The right to the highest attainable standard of health (Article 12 of the International Covenant on Economic, Social and Cultural Rights), adopted 11 May 2000, CESCR 22nd Session, UN Doc E/C.12/2000/4.

⁶ Declaration on the TRIPS Agreement and Public Health. WT/MIN(01)/DEC/W/2, adopted 14 November 2001.

⁷ Eg. see: Resolutions WHA52.19 (1999), WHA53.14 (2000), WHA54.10 (2001), WHA54.11 (2001), WHA54.13 (2001), WHA55.12 (2002).

⁸ *ILO Code of Practice on HIV/AIDS and the World of Work*, June 2001.

⁹ For a non-exhaustive review of some such cases, see: R Elliott. Access to Treatment and the Human Right to Health: Recent Developments and Future Strategies, in the composite paper "Global Treatment Access: Legal Developments and Strategies," prepared for Putting Third First: Vaccines, Access to Treatment and the Law, satellite meeting of the XIV International AIDS Conference, Barcelona, 5 July 2002 (available via www.aidslaw.ca).

¹⁰ "United Nations Entrenches Human Rights Principles in AIDS Response: Updates International HIV/AIDS and Human Rights Guidelines; Calls on Governments to Take Significant Human Rights Action." Joint UNAIDS/OHCHR press release, Geneva, 10 September 2002.

¹¹ *Ibid.*

UN Commission on Human Rights Adopts Resolutions on Access to Medication, Right to Health

In April 2002, the United Nations Commission on Human Rights adopted two resolutions that are important in the context of access to treatment. The Commission is the UN's leading body with respect to international human rights issues. It consists of 53 UN member states and meets annually. The Commission's resolutions can be found on the website of the Office of UN High Commissioner for Human Rights via www.unhchr.ch/ by clicking on "Documents of Charter-based bodies."

Access to Medication

In Resolution 2002/32, the Commission adopted by consensus an updated version of its 2001 resolution (2001/313) on "Access to medication in the context of pandemics such as HIV/AIDS." The resolution recognizes that access to medication "is one fundamental element" for progressively realizing the human right of everyone to the highest attainable standard of health, as set out in the International Covenant on Economic, Social and Cultural Rights (Article 12).

The resolution calls upon states to take a variety of steps, including the adoption of legislative and other measures, to safeguard access to medicines from restrictions by third parties, to devote resources to promote effective access, to ensure that their actions as members of international organizations take due account of the right to health, and that the

application of international agreements (such as the World Trade Organization's TRIPS Agreement on patents) supports public health policies promoting access to safe, effective, and affordable medicines. The resolution reiterates the language of the WTO's Declaration on the TRIPS Agreement and Public Health, adopted at the WTO Ministerial Conference in November 2001 in Doha, Qatar, that the TRIPS Agreement "can and should be interpreted and implemented" in a manner that supports countries' right to promote access to medicines for all. The resolution requests the UN Secretary-General to solicit comments from governments, UN bodies, and non-governmental organizations on the steps they have taken to promote and implement the resolution, and to report back to the Commission in 2003.

Rapporteur on the Right to Health

At the same session, the Commission also adopted Resolution 2002/31 on "The right of everyone to the enjoyment of the highest attainable standard of physical and mental health." The resolution provides for the appointment, for a period of three years, of a Special Rapporteur on the right to health. The rapporteur is to gather information; engage in dialogue with governments, UN bodies (including UNAIDS), non-governmental organizations, and international financial institutions (eg, the World Bank, the International Monetary Fund); report on the status throughout the world of the right to health and related laws, policies, and practices; and make recommendations on appropriate measures to promote and protect the realization of the right. The rapporteur is to submit an annual report to the Commission.

– Richard Elliott

WHO Initiatives to Increase Access to Treatment in Developing Countries

In mid-2002, the World Health Organization (WHO) estimated that some six million people with HIV/AIDS in developing countries are currently in need of life-sustaining antiretroviral (ARV) therapy, but that only 230,000 have access to these medicines, half of whom live in one country, Brazil. The WHO believes that, with a concerted international effort to expand access to HIV treatment and care, three million people could have access to ARVs by the end of 2005. A number of recent initiatives provide some useful tools toward reaching this goal.

Guidelines for ARV Therapy in Poor Countries

In June 2002, the WHO released its 165-page document providing technical guidelines to promote the rational and safe use of ARVs in poor countries through standardized regimens and simplified monitoring that is feasible in settings with limited resources.¹ The guidelines were developed through international consultations involving more than 200 clinicians, scientists, government representatives, civil society representatives, and people living with HIV/AIDS from more than 60 countries. The guidelines are based on a review of the evidence and current best practices, supplemented by expert consensus where the body of evidence was not conclusive. The guidelines will be updated as required by new evidence.

Additional materials produced by the WHO, or in collaboration with others, support the use of these guidelines to increase access to treatment in developing countries. Several tools have been released in recent months.

List of Quality-Approved Medicines and Manufacturers

In March 2002, the World Health Organization published its first list of

HIV-related medicines found to meet its recommended quality standards, as part of its "Access to Quality HIV/AIDS Drugs and Diagnostics" project. The initial list consisted of 40 products from eight brand-name and generic manufacturers, including antiretroviral drugs (allowing for several triple therapy combinations) and drugs for opportunistic infections. The WHO updates the list regularly, adding new products and suppliers that meet the WHO's quality standards. The inclusion of generic manufacturers on the list is important, assisting countries that do not have strong drug-review systems but need to access less-expensive generic medicines.

New Model List of Essential Medicines Includes ARVs

In April 2002, the WHO issued its 12th Model List of Essential Medicines, which includes 12 ARVs and over 60 other essential medicines for HIV-related care, including drugs that fight opportunistic infections. The inclusion of these drugs on the essential-medicines list is based on evidence of their efficacy in developing countries. The WHO's Expert Committee on the Use of Essential Medicines concluded these drugs can

be used effectively and safely in poor settings.

According to the WHO, two billion people, one-third of the world's population, still lack access to essential life-saving medicines "when they need them, at a quality they trust and at a price they or their community can afford."² The WHO introduced the concept of "essential medicines" in the 1970s as an important aspect of global public health. The first WHO Model List of Essential Medicines was issued in 1977, and in 1978 governments adopted the Declaration of Alma-Ata on Primary Health Care, identifying "provision of essential drugs" as one of the eight elements of primary health care. According to the WHO:

Essential medicines are those that satisfy the priority health needs of the population. They are selected with due regard to disease prevalence, evidence on efficacy and safety, and comparative cost-effectiveness. Essential medicines are intended to be available within the context of functioning health systems at all times in adequate amounts, in the appropriate dosage forms, with assured quality, and at a price the individual and the community can afford.³

Updated Information on ARV Price Reductions

As a result of concerted activism, significant reductions in drug prices have been achieved that will assist in increasing access to affordable HIV/AIDS treatment in developing countries. But the lack of clear information on the various prices available on the international market makes it

more difficult to make informed decisions and negotiate affordable prices.

In July 2002, Médecins Sans Frontières (MSF), the WHO, UNAIDS, and UNICEF issued their second, updated report on the current state of price reductions on ARVs available to developing countries.⁴ The report aims to assist developing countries “by providing them with ARV prices offered by originator companies and some generic companies in low- and middle-income countries. It is intended for use by government and non-profit procurement agencies, as well as other bulk purchasers of ARVs, including health facilities and NGOs.” The information is intended to be used in conjunction with the WHO information about quality-approved medicines and manufacturers.

Reports on Trade and Access to Medicines

In addition to producing these useful tools for accessing and using more affordable medicines in developing

countries, the WHO has also addressed the question of legal barriers to access posed by its agreement on drug patents (the “TRIPS Agreement”).

In June 2002, it released another paper in its series on essential drugs and medicines policy, entitled *Implications of the Doha Declaration on the TRIPS Agreement and Public Health*. The paper examines the significance of the Declaration adopted by the trade ministers of WTO member countries in Doha, Qatar, in November 2001. It argues that WTO panels and the Appellate Body should, in cases of ambiguity, opt for interpretations of the TRIPS Agreement that are effectively “supportive of WTO Members’ right to protect public health.” It affirms the argument put forward by some activists and commentators that the Declaration is not only a political statement, but also one with legal effects on the members of the WTO and its dispute-settlement mechanisms.

The WHO also “partnered” with the WTO to jointly produce a

175-page report on *WTO Agreements and Public Health*. The report, released in August 2002, examines the way WTO trade agreements may influence health and health policies in a variety of areas, including the question of intellectual property rights and access to drugs. The study highlights areas where the links between trade and health require more careful analysis.

– Richard Elliott

WHO materials on HIV/AIDS and access to treatment can be found online at www.who.int/hiv or www.who.int/medicines. The MSF/WHO/UNICEF/UNAIDS report on price reductions is available in English, French, and Spanish via the MSF website at www.accessmed-msf.org. The joint WHO/WTO study can be found via www.wto.org or www.who.int.

¹ *Scaling Up Antiretroviral Therapy in Resource-Poor Settings: Guidelines for a Public Health Approach*. Geneva: World Health Organization, June 2002.

² JD Quick et al. Twenty-five years of essential medicines. *WHO Bulletin* November 2002; 80(11): 913-914.

³ *Ibid.*

⁴ *Untangling the Web of Price Reductions: A Pricing Guide for the Purchase of ARVs for Developing Countries* (2d ed). MSF/WHO/UNAIDS/UNICEF, June 2002 (available via www.accessmed-msf.org).

Global Fund Decides to Promote Use of Generic Drugs

On 15 October 2002, the Executive Director of the Global Fund to Fight AIDS, Tuberculosis and Malaria announced that the Fund would “encourage” developing countries receiving money from the Fund to purchase less expensive generic medicines instead of brand-name drugs. The Fund will now advise countries applying for grants to buy the lowest-price drug, buy only drugs of guaranteed quality, and comply with

international law and their own domestic laws.¹ The Board of the Fund decided to recommend that countries use the list of approved medicines and manufacturers first issued by the World Health Organization in March 2002 and updated regularly.²

However, the Global Fund remains drastically under-resourced. As of October 2002, pledges of US \$2.1 billion, spread over five years, had been

made, but only US\$483 million had actually been deposited with the Fund. At its October 2002 meeting, the Board of the Fund forecast it would need an additional US\$2 billion in 2003 alone to finance the growing number of worthy proposals, and an additional US\$4.6 billion in 2004.³ Shortly before the Board meeting, UNAIDS and the WHO released updated estimates that US\$10.5 billion will be needed by 2005 for

prevention, care, and support programs for HIV/AIDS alone, not including the resources needed for developing health-sector infrastructure in the poorest countries.⁴

– Richard Elliott

¹ G Dyer: UN-backed AIDS fund approves generic drugs. *Financial Times*, 12 October 2002; DG McNeil Jr: UN disease fund opens way to generics. *New York Times*, 16 October 2002.

² The WHO's list of drugs and manufacturers of approved quality is updated regularly, and can be found at www.who.int/medicines/organization/qsm/activities/pilotproc/suppliers.doc.

³ GFATM Press release: The Global Fund to Fight AIDS, Tuberculosis and Malaria says: Additional \$2 billion needed next year to fund AIDS, TB and malaria programs. Geneva, 11 October 2002 (available via www.globalfundatm.org).

⁴ Joint UNAIDS/WHO Press release: New figures show AIDS fight under-resourced; existing funds insufficient to keep pace. Geneva, 10 October 2002 (available via www.unaids.org).

UK Commission Concludes International Patent Laws Hinder Access to Medicines in Developing Countries

On 12 September 2002, the UK Commission on Intellectual Property Rights, an independent body established in May 2001 by the British government, released its report analyzing the impact of international agreements on patents. The report, *Integrating Intellectual Property Rights and Development Policy*, makes 55 recommendations “aimed at aligning [intellectual property] protection with the goal of reducing poverty.”¹

In recent years, human rights activists have criticized the World Trade Organization's Agreement on Trade-Related Aspects of Intellectual Property Rights (the TRIPS Agreement), and similar “free trade” agreements on patents, as creating additional barriers for developing countries in accessing less expensive medicines. The Commission's report lends further weight to those criticisms.

The Commission's 191-page report concludes that strict patent protection regimes are not as beneficial for developing countries as for industrialized ones, because they increase the cost of many products needed by poorer countries. In releasing the report, the Chair of the Commission stated: “Developing countries should not be coerced into adopting stronger IP rights without regard to the impact this has on their development and

poor people.” Instead, the Commission recommends that regimes should be tailored to the particular circumstances of a country, including its level of economic development.

The Commission also affirms that strong patent protection “hardly plays any role in stimulating research on diseases particularly prevalent in developing countries,” unless there is also a significant market in the industrialized countries. It points out that the economic research on the impact of IP rights, even in the developed world, is inconclusive and contested, and that “many academic observers, for this reason, remain determinedly ambivalent as to whether the social benefits of IP rights exceed their costs.”

The Commission recommends that measures be available to mitigate the negative impact of strict patent protec-

tions, such as compulsory licensing of patented medicines, differential pricing arrangements with lower prices on patented medicines for poorer countries, and the parallel importation of patented products from other countries where they are sold more cheaply by the patent-holding company. The Commission also recommends delaying any implementation of the entire TRIPS Agreement by least-developed countries until at least 2016.

– Richard Elliott

The Commission's final report, as well as a series of 14 accompanying study papers and several supporting case studies from developing countries, are available via www.iprcommission.org by clicking on “Documents.”

¹ Commission on Intellectual Property Rights. *Integrating Intellectual Property Rights and Development Policy*. London: The Commission, September 2002.

Thailand: Successful Challenge to Invalid Patent Claim on Antiretrovirals

Thai people living with HIV/AIDS made legal history on 1 October 2002, when they won a lawsuit against the pharmaceutical giant Bristol Myers-Squibb (BMS).¹ The plaintiffs, two people living with HIV/AIDS and a local NGO, the AIDS Access Foundation, lodged a complaint against BMS and Thailand's Department of Intellectual Property (DIP) in Thailand's Central Intellectual Property and International Trade Court (CIPITC). They claimed that the BMS patent registration for its buffered tablet formulation of the antiretroviral AIDS drug, dydeoxy purine nucleoside (ddI, brand name Videx®), was illegally amended in an attempt to claim a wider monopoly than the patent description justified.

The court ruled for the plaintiffs. It found that by deleting the phrase "from about 5-100 mg per dose" from its patent claim, BMS had asserted exclusive ownership beyond the range originally specified in the patent registration, thereby inhibiting generic production and ensuring their monopoly on ddI in Thailand, where they charge 44 Thai baht per 100 mg tablet (42 Thai baht = \$1 US).

The BMS and DIP argued that because the plaintiffs are not manufacturers, they could not be recognized as injured parties in law and therefore did not have authority to take legal action. The court rejected this argument, finding the plaintiffs were interested (and injured) parties entitled to make their claim. The court stated that "medicine is essential for human life, as distinct from other products that consumers may or may not choose to consume," and "the treatment of life and health transcends the importance of any other property." The court noted that "this was recognized internationally" at the 4th Ministerial Meeting of the World Trade Organization (WTO) at Doha, Qatar (9-14 November 2001), where members resolved that the Agreement on Trade-Related Aspects of

Intellectual Property Rights (the TRIPS Agreement) must be interpreted and implemented so as to promote the rights of WTO members to protect public health, and in particular to promote access to medicine for all. The court therefore concluded that the parties injured by the illegal amendment of the patent could not be limited just to competing manufacturers or vendors of the medicine protected by the patent.

The court ordered that the limiting phrase regarding the dosage, which had been unlawfully deleted from the patent claim, should be restored. The court ordered BMS to pay the plaintiffs' costs of bringing the lawsuit. The defendants have 30 days to appeal the ruling.

Following the decision, activists in Thailand called on the Government to order the state-owned pharmaceutical organization (GPO) to immediately start producing generic buffered ddI in tablet form. GPO representatives said they could manufacture the drug in a buffered tablet form at half the price being charged by BMS. Until now, Thai people living with HIV/AIDS who could not afford BMS's patented ddI pill resorted to GPO-produced generic ddI in powder

form, which is more difficult to take, making it harder to adhere to the drug regimen. On 16 October, the GPO announced that it would produce a generic version of the buffered tablet in dosage ranges outside those covered by BMS's patent on 5-100 mg formulations, if it was certain that BMS would not be appealing the ruling.²

The landmark court decision has paved the way for a second case, submitted on 9 October 2002, in which the plaintiffs (three people living with HIV/AIDS and the Foundation for Consumers) assert that the defendant BMS does not demonstrate an innovation in its patent claim for ddI in Thailand and therefore the patent must be revoked.

Since 1999, AIDS activists in Thailand have publicly challenged the validity of the BMS patent on buffered ddI, on the grounds that adding an antacid to buffer the compound, a common practice among pharmacists, does not constitute an innovation. In 1999, activists demanded the invocation of a compulsory licence to produce the drug, but the Thai government refused. Paisan Tan-Ud, founding Chairman of the Thai Network of People Living with HIV/AIDS (TNP+), received a letter (dated 27 January 2000) from the United States Trade Representative promising the US would not raise objections if the Thai government decided to issue a compulsory licence to address its AIDS crisis (provided it complied with the WTO TRIPS Agreement). Though Article 31 of TRIPS permits WTO countries to use compulsory licensing, Thai Public Health and Commerce ministry officials declined to respond officially to the activists' request or to issue a compulsory licence.

Thai people living with HIV/AIDS and their NGO allies, such as the

AIDS Access Foundation, Foundation for Consumers (FFC), and Médecins Sans Frontières (MSF), will continue working with the government to find solutions to the problem of high-priced AIDS drugs that remain out of reach for most people in the country. Thai treatment activists continue to push for total coverage of antiretroviral therapy under the universal health-care system, as well as meaningful participation in enhancing comprehensive HIV/AIDS services at hospitals around the country. The next International AIDS Conference will be

held in Bangkok in 2004, providing further opportunities for activists to campaign for access to treatment and other human rights.

— Reported by Karyn Kaplan,
with information from Paul Cawthorne
and Onanong Bujumong

Karyn Kaplan is HIV/AIDS Program Officer of the International Gay and Lesbian Human Rights Commission (IGLHRC).

For further information on the case and activism in Thailand on access to treatment, see the websites of the Consumer Project on Technology (www.cptech.org/ip/health/c/thailand) and IGLHRC (www.iglhrc.org/world/se_asia/Thailand2002Oct.html), or

contact Mr Paul Cawthorne, Head of Mission, Médecins Sans Frontières in Bangkok (msfbthai@ksc.th.com), Ms Onanong Bujumong, Access Campaign Coordinator, Médecins Sans Frontières in Bangkok (msfdrugs@asianet.co.th), or Karyn Kaplan (karyn@iglhrc.org).

¹ *AIDS Access Foundation et al v Bristol Myers- Squibb Company and Department of Intellectual Property*, Black Case No. Tor Por 34/2544, Red Case No. 93/2545, Central Intellectual Property and International Trade Court, 1 October 2002 [unofficial English translation from Thai original judgment on file]. See also: K Ahmad. Thailand court forces reversal of drug firm antiretroviral patent. *Lancet* 2002; 360: 1231 (19 October 2002).

² P Theppumpanat. Thailand takes on US giant over AIDS drug. *Reuters*, 9 October 2002; Thai government to begin producing didanosine. *Kaiser Daily HIV/AIDS Report*, 18 October 2002 (with reference to *Financial Times*, 17 October 2002); S Sivaram. Patient rights win over patent rights. *Inter Press Service*, 20 October 2002.

China: Government Issues Licences for Three Antiretrovirals

The Chinese government has approved the production and sale of at least three generic antiretroviral drugs used in treating people living with HIV/AIDS. The first applications were filed in late 2001¹ and approved in August and September 2002.

In August 2002, the first generic antiretroviral drug produced domestically was approved for sale by the Chinese government. Northeast Pharmaceutical Group is a state-owned Chinese firm manufacturing the generic version of zidovudine (AZT). GlaxoSmithKline holds the patent elsewhere for AZT, but the patent expired in China in 2001. The generic drug entered the market in early September 2002.²

The same month, the Chinese State Drug Administration issued a licence to the private generic company Shanghai Desano Biopharmaceutical, authorizing it to produce its generic version of didanosine (ddI). In China, the drug is protected by a “process patent” only, held by the US company

Bristol Myers-Squibb, meaning that only the process and formulation for making the drug are patented, rather than the endproduct itself. Shanghai Desano’s generic ddI is produced through a different process and sold in powder form rather than tablets.³

Later the same month, Shanghai Desano received another licence to also produce its generic stavudine (d4T), again protected only by a process patent held by BMS. The company also stated it had applied for authorization to produce generic nevirapine.⁴

In October 2002, it was also reported that the Chinese government was expected to eliminate import tariffs and value-added taxes on imported AIDS drugs, which would

further reduce the cost of treatment.⁵ It was also reported that the government of Henan province (also known as Yunan) would be partnering with the Aaron Diamond AIDS Research Center in New York City to develop China’s largest HIV/AIDS treatment program.⁶

— Richard Elliott

¹ Two Chinese pharmaceutical firms apply to produce generic AIDS drugs. *Kaiser Daily HIV/AIDS Report*, 15 November 2001.

² L Chang. Chinese government approves sale of a domestic AIDS drug. *Wall Street Journal*, 13 August 2002; Chinese government approves domestically produced AIDS drug. *Kaiser Daily HIV/AIDS Report*, 13 August 2002; Some Chinese HIV/AIDS patients may receive domestically produced AIDS drug next month. *Kaiser Daily HIV/AIDS Report*, 19 August 2002; Chinese-produced version of zidovudine enters market. *Kaiser Daily HIV/AIDS Report*, 4 September 2002.

³ Chinese officials approve domestic production of second generic antiretroviral drug. *Kaiser Daily HIV/AIDS Report*, 16 September 2002.

⁴ C Wade. China to produce generic AIDS drugs. *United Press International*, 24 September 2002; Chinese government approves domestic production of third generic antiretroviral drug. *Kaiser Daily HIV/AIDS Report*, 26 September 2002.

⁵ Chinese government to eliminate duties and value-added taxes on imported AIDS drugs. *Kaiser Daily HIV/AIDS Report*, 16 October 2002.

⁶ Aaron Diamond Research Center; China’s Yunan province to provide combination therapy in country’s largest HIV/AIDS treatment program. *Kaiser Daily HIV/AIDS Report*, 22 October 2002.

Kenya: Legislative amendments Ease Imports of Generic Drugs

In May 2002, the new Industrial Property Act, originally passed by Parliament in June 2001, finally came into effect after ongoing lobbying by treatment activists with the Kenya Coalition for Access to Essential Medicines (KCAEM). The Act authorizes “parallel importation” of patented medicines purchased abroad, taking advantage of lower prices that may be charged in another country by a patent holder or by a company it has licensed to sell its product. The Act also allows the government to suspend patents on pharmaceuticals in the case of national health emergencies, but requires the government to give patent holders six months’ notice before issuing a licence authorizing others to make or import generic versions of patented drugs.¹

However, five weeks after it came into effect, the Act was amended in early June 2002, with no consultation with civil-society groups that had been active on the issue and reportedly without the knowledge of the Ministry of Health or the parliamentary health committee. The amendment added a provision stating that importation of generic versions of patented drugs could only be done by the owner of the patent or with the owner’s express

consent, making it in effect impossible or highly unlikely that less expensive generic drugs could ever be legally imported into Kenya.²

Following an outcry from treatment activists, in August 2002 the Kenyan Parliament removed this amendment, reinstating the possibility of compulsory licences authorizing the import of less expensive generic medicines.³

– Richard Elliott

¹ Kenyan law allowing importation, manufacture of generic AIDS drugs takes effect. *Kaiser Daily HIV/AIDS Report*, 3 May 2002.

² D Kimani. New law blocks import of HIV/AIDS generics into Nairobi. *East African* (Nairobi), 1 July 2002.

³ Kenyan Parliament removes requirement from drug importation law mandating generic importers have permission from patent holders. *Kaiser Daily HIV/AIDS Report*, 19 August 2002.

South Africa: Voluntary Licence to Generic Drug Company for Nevirapine

On 15 October 2002, the South African subsidiary of German drug company Boehringer Ingelheim announced it had granted a voluntary licence to South African generic manufacturer Aspen Pharmacare to make and sell nevirapine. Under the terms of the licence, Aspen will manufacture

generic nevirapine in South Africa and is authorized to export it to 13 other countries in the Southern African Development Community (SADC). Aspen said it expected to sell its product for about US\$1 per daily dose and that it would likely be available by late 2003 after approval from the

national Medicines Control Council.

The Treatment Action Campaign (TAC) welcomed the development but pointed out that the exclusive nature of the licence meant that a monopoly would still exist on Aspen's generic version, and called again on drug companies to issue non-exclusive voluntary licences to create competition that would drive prices down.¹

– Richard Elliott

¹ Boehringer Ingelheim grants South African generic drug company license to produce nevirapine. *Kaiser Daily HIV/AIDS Report*, 16 October 2002.

South Africa: TAC, COSATU and Allies File Complaint of Excessive Pricing

On 19 September 2002, the Treatment Action Campaign (TAC), the Council of South African Trade Unions (COSATU), the Chemical, Energy, Paper, Printing, Wood and Allied Workers' Union (CEPPWA), and eight individuals (health-care workers and people living with HIV/AIDS) launched a complaint with the country's Competition Commission against two major transnational pharmaceutical companies.¹ TAC and its allies allege that GlaxoSmithKline (GSK) has engaged in excessive pricing for its antiretroviral drugs Retrovir (zidovudine or AZT), 3TC (lamivudine), and Combivir (AZT/lamivudine), and that Boehringer Ingelheim (BI) has engaged in excessive pricing of its antiretroviral drug Viramune (nevirapine).

According to the World Health Organization (WHO), the most commonly recommended triple-drug therapy for HIV/AIDS is the combination of Combivir and Viramune. TAC's complaint is supported by evidence showing that a month's supply of this regimen costs R1176 (South African rand – about US\$117) at the prices charged by GSK and BI in South Africa, whereas the best price available internationally for this combination using generic drugs whose

quality has been approved by the WHO is R276 per month (about US\$28). This means that for the cost of treating one person with the brand-name drugs, four people with HIV/AIDS could be treated using less expensive generics.

Generic versions of these antiretroviral drugs (ARVs) are not sold in South Africa because of patent protections still in effect. TAC's complaint was preceded by nearly four years of campaigning aimed at getting brand-

For the cost of treating one person with the brand-name drugs, four people with HIV/AIDS could be treated using less expensive generics

name, patent-holding companies to issue unconditional voluntary licences, with a royalty of four to five percent of sales, to allow generic drugs into the South African market. As this has been unsuccessful, TAC and its allies decided to file the complaint alleging excessive pricing.

The Competition Act (Act No 89 of 1998) defines an "excessive price" as one that is higher than a price reasonably related to the economic value of the good or service. The complaint provides evidence and arguments making the case that GSK and BI are charging prices for their ARVs that are "grossly disproportionate" to their economic value. The material filed

includes information on the estimated research and development costs associated with each drug, the revenues of the companies, and alleged profiteering in the pharmaceutical sector.

TAC and the other complainants argue that

the existence of patent protection is not a justification for charging of a price which in all the circumstances is excessive and to the detriment of consumers. Patent protection does not entitle a firm to charge a price which bears no reasonable relation to the economic value of the good concerned.... Because high prices result in lack of access to treatment, the high prices of ARVs result in many avoidable opportunistic infections, preventable deaths and the resultant social and financial implications accompanying high levels of morbidity and mortality.... The detriment that is caused is particularly grave by virtue of its direct bearing on the ability of consumers fully to enjoy their constitutionally protected rights and in particular the rights to life, dignity and equality, and access to health care services.²

There are an estimated 4.74 million South Africans living with HIV/AIDS.³ AIDS is now the leading cause of death, and approximately 200,000 died of AIDS-related illness in 2001 alone. Without appropriate treatment, the Medical Research Council forecasts five to seven million cumulative AIDS deaths in South Africa by 2010.⁴

The Competition Commission is an independent body whose mandate is to ensure fair competition in the market, and to prevent the abuse of dominant market position by such means as excessive pricing. As provided for in the Competition Act, the complainants have requested that the Commission investigate the matter and refer it to the Competition Tribunal, with the recommendation that the Tribunal:

- order the excessive-pricing practices to stop;
- declare the conduct to be a prohibited practice, for the purpose of allowing damage claims by anyone who can establish loss or damage as a result of the excessive pricing; and

- impose an administrative penalty on GSK and BI of 10 percent of the firms' annual turnover in South Africa and its exports during the preceding financial year.

TAC has also called upon the South African government to resolve the matter quickly by issuing compulsory licences under the Patents Act to authorize the sale of generic ARVs in the country.

– Richard Elliott

The TAC complaint, 18 supporting affidavits, and additional information about the proceeding can be found on the TAC website via www.tac.org.za by clicking on "Documents." TAC is a grassroots organization campaigning for greater access to treatment for all South Africans living with HIV/AIDS.

¹ *Treatment Action Campaign & Others v GlaxoSmithKline South Africa (Pty) Ltd & Others*. Statement of Complaint in Terms of Section 49B(2)(b) of the Competition Act 89 of 1998.

² Statement of Complaint, paras 46, 50-51.

³ National Department of Health. 12th National HIV and Syphilis Seroprevalence Survey in South Africa (2001).

⁴ Medical Research Council. The Impact of HIV/AIDS on Adult Mortality in SA (2001).

WTO: US and Argentina Settle Dispute over Patents and Data Protection

In May 2000, supplementing an earlier complaint filed in May 1999, the US filed a complaint against Argentina, alleging that its patent laws violate the World Trade Organization's Agreement on Trade-Related Aspects of Intellectual Property (the TRIPS Agreement). The gist of the US complaint was that Argentina's law failed to provide: (1) adequate protection against "unfair" commercial use of undisclosed test data submitted in order to get market approval of pharmaceutical products; (2) certain safeguards for compulsory licences on an invention granted on the basis of inadequate working by the patent holder; and (3) adequate measures to prevent infringements of patent rights. The US also alleged that Argentina denies certain exclusive rights of patent holders, such as the exclusive right to import the patented product into the country.¹ At the end of May 2002, the US and Argentina notified the WTO that they had reached a "mutually agreed solution," without prejudice to their respective rights and obligations under WTO agreements, and the US has withdrawn its complaint.²

Among other things, the two countries have agreed that Argentina will not grant compulsory licences to remedy anticompetitive practices by patent holders unless the Argentinean competition tribunal finds there has been an "abuse of a dominant position in the market." In this respect, Argentinean law goes beyond what is required by TRIPS, which gives countries wide latitude to use compulsory licensing to remedy practices found to be "anticompetitive," without mention of any additional criteria or qualifications as to which anticompetitive practices justify granting a compulsory licence.

The US and Argentina also agreed that Argentina will grant five years' exclusive marketing rights on a product after approving it for marketing in the country or until a patent on the product is granted or rejected, if a patent has been applied for in Argentina and the product has been patented or been granted exclusive marketing rights in another WTO member country.

Argentina also agreed to introduce legislation amending its laws on cases of alleged patent infringement. That legislation is currently before the national legislature. The US has indicated that it will "assess" the progress

of these amendments, and "in the light of this assessment" it may decide to renew its complaint at the WTO regarding inadequate protection for patent holders against "unfair commercial use" of their test data submitted for gaining market approval of their pharmaceutical products.

The agreement reaffirms that Argentina is free to allow "parallel imports" of a patented product into the country by someone other than the patent holder where the product has been put on the market in a foreign country by the patent holder or with its consent. This is permitted under the TRIPS Agreement and means a patented product sold more cheaply elsewhere can be purchased there and imported into Argentina.

– Richard Elliott

¹ Argentina – Certain Measures on the Protection of Patents and Test Data, complaint by the United States, WT/DS196/1 (30 May 2000). See summary in: R Elliott, Complaint against Argentina over protection of patents and test data. *Canadian HIV/AIDS Policy & Law Review* 2000; 5(4): 29. The earlier complaint was: Argentina – Patent Protection for Pharmaceuticals and Test Data Protection for Agricultural Chemicals. Complaint by the United States, WT/DS171 (6 May 1999). WTO documents are available online via www.wto.org/.

² Notification of Mutually Agreed Solution According to the Conditions Set Forth in the Agreement. WT/DS171/3, WT/DS196/4 (20 June 2002).

Inter-American Commission on Human Rights Holds Hearing on Access to Treatment in Latin America and the Caribbean

In a historic development, non-governmental HIV/AIDS organizations in Latin America and the Caribbean presented a joint report on access to comprehensive care, including antiretroviral (ARV) drugs, to the Inter-American Commission on Human Rights on 16 October 2002.¹

The report was prepared by the Agua Buena Human Rights Association, the Latin American and Caribbean Council of AIDS Service Organizations (LACCASO), and the Center for Justice and International Law (CEJIL), with the collaboration of 28 other NGOs. The report aims to raise Commission members' awareness of the human rights abuses faced by people living with HIV/AIDS in the region. In particular, it makes the case for the Commission to become more active in addressing the widespread lack of access to care and treatment, which represents a denial of human rights to people living with HIV/AIDS.

The report provides an overview of the current situation with respect to access to comprehensive care, including ARVs, in most countries of the region, and summarizes the commitments made by Latin American and Caribbean states in various forums to improve access to care for people living with HIV/AIDS. The report indicates the lack of follow-through on these commitments.

The report reviews the use of the constitutional remedy of *amparo* in various countries to secure court orders compelling the government to

provide HIV/AIDS treatment. *Amparo* is a remedy in Latin American civil law systems best described as a "constitutional injunction" – ie, an injunction sought urgently to redress an existing breach of constitutional rights or to prevent an imminent breach.

The report also discusses the experience of seeking redress before the Inter-American Commission to obtain access to ARV medicines. In urgent cases, the Commission may request states to adopt "precautionary measures" to avoid serious and irreparable harm to human rights. The Commission has ordered "precautionary measures" in El Salvador, Ecuador, the Dominican Republic, Peru, Bolivia, Nicaragua, Guatemala, Chile, and Honduras. In 2001, it agreed to hear a petition filed by a Chilean NGO in order to assess the state of access to ARVs in that country more generally. The report provides an update on requests for such orders in nine countries.

However, the report indicates that even in cases where the Commission has ordered "precautionary measures," the governments in question are not complying with the order and most people living with HIV/AIDS continue without access to medicines and

some have died as a result of governments' refusal to act or delay acting.

The NGOs have therefore asked the Commission to appoint a special rapporteur or, alternatively, a specialized unit with appropriate training and the capacity for rapid action, to address the denial of human rights to people living with HIV/AIDS. They also requested that the Commission give priority to petitions requesting precautionary measures aimed at securing access to treatment for people living with HIV/AIDS. Finally, given the urgency of these cases and the failure of many states to comply with Commission orders, the NGOs asked the Commission to follow up on this urgent human rights issue by, for example: shortening the periods for states to report on their compliance with Commission orders; requesting orders for "provisional measures" from the Inter-American Court of Human Rights; including a regular section in the Commission's annual reports tracking the human rights situation in the region for people living with HIV/AIDS; and issuing a Commission report on the obligation of states to provide comprehensive care, including ARVs, to people in need.

– Richard Elliott

The report can be obtained from LACCA-SO, the Latin American and Caribbean Council of AIDS Service Organizations. The non-governmental organization Acción Ciudadana Contra el SIDA (ACCSI – Citizen Action against AIDS) in Caracas, Venezuela, currently serves as the LACCA-SO secretariat, and can be contacted at lacaso@internet.ve. The ACCSI website is www.internet.ve/accsi. More information about the Inter-American regional human rights system can be found at www.cidh.org. More information about treatment access in Central America can be found on the Agua Buena website at www.aguabuena.org.

¹ *Informe sobre el situación de los derechos humanos de las personas que viven con VIH/SIDA y acceso a la atención integral y los tratamientos antirretrovirales (ARV) en América Latina y el Caribe* [Report on the human rights situation for persons living with HIV/AIDS and access to comprehensive care and antiretroviral treatments in Latin America and the Caribbean]. Presented to the Inter-American Commission on Human Rights by Agua Buena Human Rights Association (Costa Rica), Latin American and Caribbean Council of AIDS Service Organizations (LACCASO) (Venezuela), and Center for Justice and International Law (CEJIL) (Washington), 16 October 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. 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.

BC Court Orders Government to Pay for Treatment

On 9 October 2002, the British Columbia Court of Appeal upheld a ruling of a BC court that the BC government must not discriminate against a disabled and disadvantaged group when choosing what medical treatments it will fund. The Court of Appeal ordered the BC government to pay for a particular form of treatment. The case is significant in the context of HIV/AIDS because it could lend support to arguments that a government must make appropriate accommodation for the health-care needs of other disabled and marginalized groups – for example, safe injection supervision for the treatment of addiction.

In *Auton (Guardian ad litem of) v British Columbia (Minister of Health)*,¹ the petitioners sought a declaration that the denial of funding for a particular treatment for autism called Lovaas Autism Treatment (LAT) violated sections 7 and 15 of the *Canadian Charter of Rights and Freedoms*.² They also sought an

order of mandamus requiring the Crown to pay for the costs of LAT.

The *Auton* case turned on a comparison of services provided to autistic children relative to other people with mental disabilities or to other children. In other words, the basis of the argument was that these autistic children were not receiving services

“Canadians are entitled to expect medical treatment for their physical and mental diseases.”

that other children and/or adults with mental disabilities were receiving.

The primary relief sought by the petitioners was an order that the Medical Services Commission and the Ministry of Health provide LAT as a medical benefit under the province’s medicare scheme.

The petitioners maintained that LAT was a “medically necessary service” insofar as it significantly improved the condition of autistic

children. The Crown questioned the proven efficacy of LAT and rejected it as a “medically necessary service.” The trial judge concluded that, regardless of the debate in the medical journals, there was no dispute that early-intervention behavioural therapies assisted many children with autism to achieve significant social and educational gains. The judge examined the provisions of the relevant legislation,³ and the expert evidence adduced, and determined that intensive behavioural treatment was a “medically necessary service.” The judge concluded:

Canadians are entitled to expect medical treatment for their physical and mental diseases. This is so, even where a disease cannot be “cured.” I conclude that the legislative framework does not preclude the delivery of early intensive ABA [applied behaviour analysis] treatment to autistic children, where appropriate, within B.C.’s medicare scheme.⁴

The petitioners also argued that the decision not to fund effective treatment for autism neglected to take into account the disadvantaged position of autistic children and resulted in substantively different treatment, placing an additional burden on them that was not suffered by non-autistic children or mentally disordered adults.

The court agreed. It found that, in failing to make appropriate accommodation for their health-care needs, the Crown had discriminated against children with autism. (It was not the medicare legislation that was discriminatory or defective but the Crown’s overly narrow interpretation of it.) This was determined to be direct discrimination, with the appropriate comparator groups being non-autistic children or mentally disabled

adults. Compared with non-autistic children, the infant petitioners were subject to differential treatment based on the enumerated ground of mental disability. Compared with mentally disabled adults, they were subject to differential treatment based on the enumerated ground of age.

Further, the court found that the absence of treatment programs must have been based on the premise that autistic children cannot be treated effectively. The evidence in the case showed this assumption to be based on a stereotype, a misconception. The stigma attached to mental illness is historical and widespread. The court concluded that only effective treatment can reduce the marginalization of autistic children and their exclusion from mainstream society.

The court found it unnecessary to consider adverse-effects discrimination. The petitioners were the victims of the government’s failure to accommodate them by failing to provide treatment to ameliorate their mental disability. That failure constituted direct discrimination.

In summary, the court found that the petitioners had established that their s 15 rights had been infringed. The Crown had failed to take into account and accommodate the infant petitioners’ already disadvantaged position, resulting in differential treatment. That unequal treatment, which was based on the enumerated ground of mental disability, was discriminatory. The only accommodation possible was funding for effective treatment.

The Charter breach was not justified under s 1. While it was irrefutable that health-care resources are limited, it was not possible to estimate accurately either the additional immediate costs of a treatment

program or the inevitable savings in the long run.

In a broad sense, it [was] apparent that the costs incurred in paying for effective treatment of autism [might] well be more than offset by the savings achieved by assisting autistic children to develop their educational and societal potential rather than dooming them to a life of isolation and institutionalization.⁵

The petitioners were entitled to a declaration that the Crown had violated their s 15(1) rights.

The Crown appealed the above declaration and a remedial order, saying that denial of funding for treatment of autism did not breach the infant petitioners’ s 15 rights and that if there was such a breach, it was justified pursuant to s 1 of the Charter. The petitioners cross-appealed on the remedy, saying that the treatment ordered was insufficient to remedy the Charter breach and that the sums ordered to be paid as damages were also insufficient. In a judgment released on 9 October 2002, the Court of Appeal upheld the trial judge’s finding of discrimination. While the Court of Appeal acknowledged that not all refusals to treat a health-care problem would be seen as discrimination, it concluded:

The failure of the health care administrators of the Province to consider the individual needs of the infant complainants by funding treatment is a statement that their mental disability is less worthy of assistance than the transitory medical problems of others. It is to say that the community was less interested in their plight than the plight of other children needing medical care and adults needing mental

health therapy. This is a socially constructed handicap within the oversight, in my view, of s. 15 of the Charter.⁶

The Court of Appeal noted that the principle that government monies should be allocated only by the legislature, while strong, did not always prevail when the issue is compliance with the Constitution. The expenditure of funds the court's decision might entail was not so extraordinary that the court had to conclude that s 1 justified the state's failure to fund treatment for autism.

– Diane Janisse

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¹ [2000] BCJ No 1547; [2000] 8 WWR 227; 78 BCLR (3d) 55 (BCSC), aff'd sub nom. *Auton (Guardian ad litem of) v British Columbia (Attorney General)* [2002] BCJ No 2258 (BCCA).

² Part I of the Constitution Act, 1982, Schedule B to the Canada Act 1982 (UK), 1982, c 11 (Charter).

³ *Canada Health Act*, RSC 1985, c C-6; the *Medicare Protection Act*, RSBC 1996, c 286 and regulations made thereunder; and the *Ministry of Health Act*, RSBC 1996, c 301.

⁴ *Auton* (BCSC), supra, note 1 at para 109.

⁵ *Ibid* at para 147.

⁶ *Auton* (BCCA), supra, note 1 at para 51.

Discrimination in Same-Sex Survivor Amendments to the Canada Pension Plan

On 31 July 2002, the British Columbia Supreme Court granted certification of a class proceeding involving same-sex surviving spouses who were denied survivor's benefits under the Canada Pension Plan¹ (CPP) due to their sexual orientation.² On 10 July 2002, a similar proceeding in Ontario survived a motion to strike by the government and is headed to trial.³ If successful, thousands of gay men and women whose same-sex partners died between 17 April 1985 and 1 January 1998 may finally be eligible for monthly survivor's benefits.

Background

As previously reported in this publication,⁴ on 31 July 2000, Bill C-23, the *Modernization of Benefits and Obligations Act*⁵ came into effect. Its stated purpose was to amend over 60 different federal statutes to recognize gay and lesbian common-law couples as legal equivalents of heterosexual common-law couples.

Of importance to many people affected by HIV/AIDS were the changes made to the CPP. Under the CPP, when a person's spouse or common-law partner dies, the surviving partner may be eligible for a monthly survivor's pension. To be eligible for the pension, the deceased person must have made sufficient contributions to the CPP while alive, and the survivor must be over 35 years of age. (Survivors under 35 are eligible if they are disabled, or are the primary caregiver of one of the children of the deceased partner.)⁶ Until the Act was passed, same-sex survivors were not eligible for the pension (although a number of same-sex survivors obtained benefits by appealing and settling their cases with the government). With the passage of Bill C-23, same-sex survivors became eligible for the pension, but only where their partner died after 1 January 1998.⁷

Furthermore, even where the partner died after 1 January 1998, no pension benefits are payable to same-sex survivors for any month prior to July 2000.⁸ (Normally, benefits are payable starting with the month following the date of death of the deceased partner.) There are no similar limiting dates in the CPP for opposite-sex common-law partners. (Opposite-sex common-law partners were included in the CPP for the purposes of survivor's pensions as of 1 January 1987.)

As a result, there are still significant negative differences between the way the CPP treats same-sex survivors as compared with opposite-sex survivors. The BC and Ontario class actions were brought on behalf of same-sex survivors whose partners died prior to 1 July 1998 but after the *Canadian Charter of Rights and Freedoms*⁹ came into effect on 17 April 1985.¹⁰

Brogaard – the BC Class Action

In *Brogaard*, the proposed class for certification was all same-sex survivors whose partners died in the relevant ineligibility period who were resident in British Columbia. In the action, the plaintiffs claimed damages

for breach of fiduciary duty, unjust enrichment, and for breach of their equality rights under s 15 of the Charter.

In resisting the certification application, it was the position of the Crown that it was “plain and obvious” that the causes of action as pleaded could not succeed. Furthermore, it was the “Crown’s position ... that the provisions of Bill C-23 are unusually generous, granting benefits retroactively instead of prospectively, as is the norm.”¹¹ (The “retroactive” aspect of Bill C-23 referred to by the Crown is that Bill C-23 was passed in July 2000, but permitted benefits to be paid to those whose spouses had died prior to that – after 1 January 1998.) The Crown also argued that the existing appeal process was sufficient to allow the plaintiffs to proceed and resolve their claims and that a separate class action was therefore not necessary.

In rejecting the Crown’s arguments, Allan J concluded that it was not obvious that the causes of action as pleaded could not succeed and that “a class proceeding is the preferable procedural vehicle for the fair and efficient resolution of the common issues.”¹²

Hislop – the Ontario-Based Action

Like *Brogaard*, the plaintiffs in *Hislop* sought certification of their action as a class action and pleaded breach of fiduciary duty and unjust enrichment, and sought damages under the Charter. However, *Hislop* also included claims based on remedial constructive trust and an equitable lien.

The proposed class in *Hislop* included all same-sex survivors whose spouses had died in the rele-

vant period and lived in provinces other than BC and Québec. (Québec has contracted out of the CPP with the federal government and has its own parallel pension plan, the Québec Pension Plan,¹³ which is not the subject of either of the class actions.)

But prior to the certification hearing, the Crown brought a motion to strike most of the statement of claim on the grounds that it failed to disclose a reasonable cause of action and pleaded insufficient facts to support the claims. The Crown also alleged that some of the paragraphs in the statement of claim were “scandalous, frivolous or vexatious and constitute[d] an abuse of process.”¹⁴ Those paragraphs alleged that the Crown was aware of the unconstitutionality of the provisions in question and had

deliberately adopted a practice of dealing with claims by same-sex survivors in a manner calculated to take advantage of their vulnerability arising from ... [their stigmatization], the reluctance of many members of the putative class to undergo public exposure through litigation and the physical illness that has afflicted some of them and many of their deceased same-sex partners.¹⁵

The plaintiffs had alleged in effect that the federal government had adopted a bad-faith litigation strategy in settling at the last moment with individual same-sex survivors who had appealed the denial of benefits within the Review Tribunal system on the grounds of unconstitutionality. The plaintiffs further alleged that this strategy was adopted in order to avoid a binding judicial determination that the provisions were discriminatory.

In detailed, careful reasons, Cullity J rejected the Crown’s motion to strike and ruled that the paragraphs the Crown objected to as scandalous were not objectionable, given the nature of the claims pleaded.

Prior to the certification hearing in *Hislop*, the Crown notified plaintiffs’ counsel that it would not be opposing certification. It is anticipated that the BC case of *Brogaard* will be stayed and *Hislop* amended to include the BC class so that one action can go forward in an expeditious manner.¹⁶

– Ruth Carey

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¹ RSC 1985, c C-8 (CPP).

² *Brogaard v Canada (Attorney General)*, [2002] BC No 1775 (QL) (BCSC).

³ *Hislop v Canada (Attorney General)*, [2002] OJ No 2799 (QL) (OSC).

⁴ See: Federal law recognizes same-sex “common-law partners.” *Canadian HIV/AIDS Policy & Law Review* 2000; 5(4): 18.

⁵ SC 2000, c 12 (the Act).

⁶ Section 44, CPP.

⁷ Subsection 44(1.1), CPP.

⁸ Subsection 72(2), CPP. Neither of the class actions addresses the differential treatment of same-sex survivors whose partners died after 1 January 1998 but before 1 July 2000.

⁹ Part I of the *Constitution Act, 1982*, Schedule B to the *Canada Act 1982* (UK), 1982, c 11 (Charter).

¹⁰ The 17 April 1985 date was chosen despite the fact that opposite-sex common-law partners were not included in the CPP survivor provisions until 1987. The stated reason for the choice of date was that the plaintiffs were arguing that the appropriate group to compare themselves to was married couples, not opposite-sex common-law couples.

¹¹ *Brogaard*, supra, note 2 at para 16.

¹² *Ibid.* at para 141.

¹³ RSQ 1965, c R-9 (QPP).

¹⁴ *Hislop*, supra, note 3 at para 9.

¹⁵ *Ibid.* at para 23.

¹⁶ Personal communication with Patricia A LeFebour of Toronto’s McGowan Elliott & Kim LLP, Barristers & Solicitors, counsel for the plaintiffs in *Hislop*.

Supreme Court Denies Leave to Appeal in Tainted-Blood Case

On 5 September 2002, the Supreme Court of Canada denied leave to appeal without reasons in *Robb, Rintoul, and Farrow*.¹ The cases involved three hemophiliacs who had been infected with HIV through the blood supply in 1985 and who had elected not to share in the settlement package negotiated with the Red Cross.² The plaintiffs and their families had for the most part been successful at trial, but in June 2000 the

Court of Appeal of Ontario overturned the trial decision.³ In dismissing the application for leave to appeal, the Supreme Court of Canada ordered the plaintiffs to pay court costs. Press reports indicate those costs may be as high as \$1 million.⁴

– Ruth Carey

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¹ The Supreme Court's decision not to grant leave to appeal in all three cases can be found at [2002] SCCA No 44 (QL), indexed under *Robb v St. Joseph's Health Care Centre*.

² For more information about the settlement package, see: R Elliott. Court approves final Red Cross bankruptcy plan to compensate blood victims. *Canadian HIV/AIDS Policy & Law Review* 2000; 5(4): 8.

³ *Robb v St. Joseph's Health Centre; Rintoul v St. Joseph's Health Centre; Farrow v Canadian Red Cross Society*, (2001) 152 OAC 60; 9 CCLT (3d) 131; [2001] OJ No 4605 (CA), rev'g [2000] OJ No 2396 (QL) (OSCJ). An extensive analysis of the Court of Appeal's decision can be found at: R Elliott. Ontario appellate court overturns judgment for plaintiffs infected through tainted blood. *Canadian HIV/AIDS Policy & Law Review* 2002; 6(3): 62-63.

⁴ S Bailey. Supreme Court dismisses tainted-blood lawsuit launched by hemophiliacs. CP Wire, Friday, 6 September 2002.

Supreme Court Denies Leave to Appeal in Medical Marijuana Charter Challenge

As previously reported in this publication,¹ in January 2002 the Ontario Court of Appeal denied Jim Wakeford's claim that Canada's laws prohibiting marijuana possession and cultivation infringe his constitutional rights to liberty and security of the person. On 22 November 2002 the Supreme Court of Canada announced that it would not hear his appeal from that decision.²

Wakeford had turned to the courts for a declaration of unconstitutionality, alleging that his Charter³ rights had been infringed because the state has denied him access to a safe, clean, and affordable source of medicinal marijuana. He also sought an order that any person acting as a caregiver to him was exempt from charges of possession, trafficking, or cultivation while engaged in assisting with his medicinal needs. Through a series of narrow technical rulings, the Court of Appeal had avoided

addressing the central substantive claims advanced by Wakeford – that it is unacceptable to force sick people to grow a medicine they are legally entitled to use, and that it is unfair to subject their caregivers to possible criminal charges for helping them obtain that medicine.

– Richard Elliott & Ruth Carey

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Executive Director of the HIV & AIDS Legal Clinic (Ontario). She can be reached at careyr@lao.on.ca.

¹ R Elliott. Ontario appellate court denies HIV-positive man's constitutional claim to medical marijuana. *Canadian HIV/AIDS Policy & Law Review* 2002; 6(3): 56-58.

² *Wakeford v Her Majesty the Queen in Right of Canada (Ont)*, [2002] SCC File No 29136.

³ *Canadian Charter of Rights and Freedoms*, Part I of the Constitution Act, 1982, Schedule B to the *Canada Act 1982 (UK)*, 1982, c 11.

Vancouver Island Compassion Club President Receives Absolute Discharge

On 5 July 2002, the BC Provincial Court released written reasons for sentencing in *R v Lucas*.¹ The president of the Vancouver Island Compassion Club had been arrested and charged with possession for the purpose of tracking after police searched the club and his home and seized less than three kilograms of marijuana.

The club had operated without incident and with the apparent tacit approval of police for 14 months. The club was broken into and two pounds of marijuana were stolen. The theft was reported to the police, who then launched an investigation that led to the charges against the club's president. (The president had nothing to do with the theft.)

In granting an absolute discharge, Higinbotham J made a number of findings of fact condemnatory of the federal government's regulatory scheme for granting medical mari-

juana exemptions and its failure to provide a safe supply. (The Crown had argued that the compassion club's activities were not necessary in light of the new process for obtaining exemptions to possess marijuana.²) The Court stated:

This case must be viewed in a broad context, in which to date, the combination of federal regulations and College of Physicians trepidation has made it extremely difficult for applicants to obtain approval to use marijuana. Further, the federal government

has so far been unable to ensure any legal supply of marijuana to those whom Health Canada thinks need it as a therapy. This is a particular hardship for those who cannot grow it.... [We] need as a society to get this thorny issue resolved quickly by either Parliament or the Supreme Court of Canada.³

— Ruth Carey

Ruth Carey is the Executive Director of the HIV & AIDS Legal Clinic (Ontario). She can be reached at careyr@lao.on.ca.

Statistics as to the number of exemptions that have been issued as well as press releases concerning upcoming clinical trials of research grade marijuana are available on the website of Health Canada's Office of Cannabis Medical Access via www.hc-sc.gc.ca/hecs-sesc/ocma/whatsnew.htm.

¹ [2002] BCJ No 1631, 2002 BCPC 268 (QL).

² See: J Gold, R Elliott. New regulations on medicinal marijuana. *Canadian HIV/AIDS Policy & Law Review* 2001; 6(1/2): 10.

³ *Ibid* at paras 47 and 49.

BC Court of Appeal Refuses to Reduce Sentence for HIV-Positive Prisoner

On 9 May 2002, the BC Court of Appeal released its decision in a prisoner's sentencing appeal where the Crown and the defence agreed that the original sentence was illegal, and differed in their positions as to the appropriate sentence by only one day.¹ That one day meant the difference between serving the sentence in a provincial jail as opposed to a federal penitentiary.

The appellant had argued that Kent Institution, the federal penitentiary where he was housed, was failing to meet his medical needs and that the provincial jail system was better situated to providing the necessary care

related to his HIV illness. Southin JA for the court rejected the argument out of hand, stating:

The events which take place after the beginning of a sentence were not truly relevant [on a sen-

tencing appeal].... Furthermore, I do not consider how a prison operates, whether it be provincial or federal, is the business of this Court. Generally speaking, we are not concerned with how the medical system works any more than we are concerned with whether one or other of the series of institutions which exists provides better meals to the prisoners.²

It was the Crown's position that the appellant's record was so extensive that he had, in effect, "graduated" to

federal penitentiary sentences. The court agreed and the sentence was fixed at two years' incarceration with three years' probation.

– Ruth Carey

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¹ *R v Brodrick*, [2002] BCJ No 988; 2002 BCCA 294 (BCCA).

² *Ibid* at para 8.

Criminal Law and HIV Transmission/Exposure: More New Cases

In a regular column we review new developments in the area of criminal prosecutions for HIV transmission or exposure.¹ Since the last issue of the *Review*, several new Canadian cases have come to our attention, including the first case in Canada in which criminal charges have been laid for sex without disclosure of hepatitis C status.

Court Rules: No Legal Obligation to Disclose Hepatitis C Infection to Sexual Partner

On 29 October 2002, a judge of New Brunswick's Court of Queen's Bench (Trial Division) acquitted Darren Jason Jones, a man with hepatitis C virus (HCV), on two counts of aggravated assault for not disclosing his HCV-positive status to two male sexual partners.² This is the first case in Canada in which criminal charges have been laid for sex without disclosure of HCV status.

The Crown argued that his non-disclosure vitiated his partners' consent to unprotected oral and anal sex, and it was therefore an "assault" under the *Criminal Code* (s 268). It also argued the risk of infection with HCV endangered the lives of the complainants, meaning the assault was an "aggravated" one. In the 1998 case of *R v Cuerrier*,³ the Supreme Court of Canada had ruled that a man who did not disclose his HIV-positive status to two women with whom he had unprotected penetrative sex could be charged with aggravated assault. The court ruled that the duty to disclose would arise where there was a "signif-

icant risk" of HIV transmission.

Garnett J ruled that, given the available evidence, she did not believe the first complainant's testimony that he was unaware of Jones's HCV-positive status. Therefore, she concluded that the prosecution had not proved a lack of consent on his part and dismissed the first charge of aggravated assault.

The judge did accept that the second complainant was unaware of Jones's HCV infection. But she also found that Jones and the complainant had never discussed his health status and that Jones had been told on at least one occasion that he did not

need to inform his sexual partners of his HCV-positive status. In addition, an expert witness and physician testified that he does not advise his patients to disclose their HCV-positive status because of the stigma associated with the disease. Garnett J concluded that the risk of sexual transmission of HCV was less than one percent in the case of monogamous heterosexual couples, and somewhere between one and 2.5 percent for "those engaging in anal sex"; so the risk of transmission through unprotected sex "is so low that it cannot be described as significant." Therefore, Jones had no positive legal duty to disclose his status to his sexual partner and was accordingly acquitted on the second count.

Supreme Court of Canada Hears First Appeal Since *R v Cuerrier* Concerning Non-Disclosure and Unsafe Sex

In a previous article in the *Review*⁴ we reported on the decision of the Newfoundland Court of Appeal in *R v Williams*.⁵ Since then, *Williams* has been appealed by the Attorney General for Newfoundland to the Supreme Court of Canada. The Attorney General for Ontario sought and obtained leave to intervene at the Court and a publication ban is in place.⁶ Oral arguments were heard on 3 December 2002 and, as of the date of writing, the decision in the case is reserved.

Williams involves a different situation than that before the court in *R v Cuerrier*.⁷ In *Williams*, the complainant was infected by the accused, but it is unknown whether or not the infection occurred before or after *Williams* discovered his HIV-positive status.⁸ *Williams* was charged with aggravated assault, criminal negligence causing bodily harm, and common nuisance. The trial judge found *Williams* guilty of aggravated assault and common nuisance and not guilty of criminal negligence causing bodily harm. On appeal, the Court of Appeal dismissed the appeal on the conviction of common nuisance. The majority of the Court of Appeal allowed the appeal against conviction for aggravated assault and entered a conviction for attempted aggravated assault. A minority of the Court of Appeal would have dismissed the appeal against conviction on the charge of aggravated assault, having dissented from the determination that the Crown had not proven beyond a reasonable doubt that the respondent endangered the complainant's life.

Québec: Woman Sentenced to More Than Three Years in Prison for Biting

In September 2002, an HIV-positive woman charged with aggravated assault for biting another woman's

thumb to the bone was sentenced in Québec City to several years' imprisonment. Guylaine Labrecque is a 39-year-old sex worker who is also living with hepatitis B and C. In March 2002, while heavily intoxicated, she got into an altercation with the victim at a bar. The victim began post-exposure prophylaxis. She was not infected with hepatitis and, at the time of sentencing, she continued to test HIV-negative. Labrecque had a lengthy criminal record. The court imposed a sentence of three years in prison, taking into account that she had spent six months in pretrial custody. The sentencing judge stated that "it is necessary to dissuade HIV carriers from putting the lives of others in danger in using the virus as a weapon." Labrecque was also ordered to provide bodily samples for genetic testing. The decision was reported only in the media.⁹

Alberta: Court of Appeal Refuses to Increase Sentence for Biting of Police Officer by HIV-Positive Hit-and-Run Driver

In the March 2002 edition of the *Review*, we reported that on 18 January 2002, a jury had found an Edmonton man with HIV guilty of assault causing bodily harm for having bitten a police officer and saying

"Welcome to the world of AIDS."¹⁰ In the early hours of 1 January 2001, the accused, Russell Debnam, fishtailed his car around a corner and struck a pedestrian waiting for a cab. He drove off, fleeing the scene, and a few hours later an officer came to his house and arrested him. A scuffle ensued and the officer was bitten, the skin being punctured. After the conviction, Mr Debnam was sentenced to two years for assault causing bodily harm and resisting arrest as a result of the biting altercation. The two years were to be served consecutively to two concurrent one-year sentences resulting from the hit and run.

The Crown appealed and argued that the assault should have resulted in a longer sentence of three years, and that the sentences for all counts should have been consecutive (increasing the total sentence from three years to at least five).

On 7 October 2002, the Court of Appeal rejected the Crown's appeal with respect to the assault.¹¹ In doing so the Court appeared to approve the trial judge's view that the comments made by Mr Debnam about the possible transmission of HIV to the officer as a result of the bite were "a serious aggravating factor." In addition, the Court of Appeal approved the following statement made by the trial judge:

Police officers in this city have a right to expect, when properly carrying out their duties, that they should not be subjected to rudeness, abuse and assault. They should certainly not be expected to be assaulted in a manner whereby their health and safety, as well as their family's health and safety may be placed in jeopardy.¹²

However, the Court did grant the Crown's appeal with respect to the dangerous driving and hit-and-run

charges, ruling that they should have been made consecutive rather than concurrent. The end result was that the sentence was increased from three years to four.

Ottawa: Four and a Half Years for Having Sex and Failing to Disclose HIV-Positive Status

The *Ottawa Citizen* reported that on 18 June 2002, White J of Ontario's Superior Court of Justice sentenced an HIV-positive man to four and a half years in jail (including six months in pretrial custody) for a single sex act in which he had failed to disclose his HIV-positive status in advance.¹³ No details are available concerning the specific charge or whether the disposition resulted from a guilty plea.¹⁴

Kitchener: Ten-Year Sentence for HIV-Positive Man

According to press reports,¹⁵ on 28 June 2002 an HIV-positive man living in Kitchener, Ontario, was sentenced to ten years in prison after pleading guilty to four counts of aggravated assault and one count of causing bodily harm. Edgard Monge discovered he was HIV-positive in

November 1999, just days before his wife died from AIDS. Shortly thereafter he began the first of the four sexual relationships that led to the charges. According to reports, Mr Monge failed to inform his partners of his HIV-positive status although he had been counselled by a physician to do so. Two of the four women subsequently became infected as a result.¹⁶ One of the women became pregnant with Mr Monge's child, who was also subsequently diagnosed as HIV-positive.

– Ruth Carey & Richard Elliott

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¹ See, eg, R Elliott. Criminal law and HIV transmission/exposure: one new case. *Canadian HIV/AIDS Policy & Law Review* 2002; 7(1): 52.

² *R v Jones*, [2002] NBJ No 375, 2002 NBQB 340 (QL).

³ *R v Cuerrier*, [1998] 2 SCR 371. See summary at: R Elliott. Supreme Court rules in *R v Cuerrier*. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(2/3): 1, 17-24.

⁴ R Elliott. Newfoundland: First case to reach appellate courts since *R v Cuerrier*. *Canadian HIV/AIDS Policy & Law Review* 2002; 6(3): 64-66.

⁵ *R v Williams* (2001), 205 Nfld & PEIR 1; (2001) 158 CCC (3d) 523 (NCA) ("*Williams*").

⁶ *R v Williams*, [2001] SCCA No 561.

⁷ *R v Cuerrier*, [1998] 2 SCR 3271; 127 CCC (3d) 1.

⁸ In *R v Cuerrier*, the accused was aware of his HIV-positive status throughout his relationships with the complainant women, but none of his sexual partners appeared to have become infected as a result. See: Supreme Court rules in *R v Cuerrier*, supra, note 3. For an in-depth analysis of that decision, including a discussion of a possible "safer sex" or "lower risk" defence to assault charges, see: R Elliott. *After Cuerrier: Canadian Criminal Law and the Non-Disclosure of HIV-Positive Status*. Montréal: Canadian HIV/AIDS Legal Network, 1999 (at www.aidslaw.ca/Maincontent/issues/criminalaw.htm).

⁹ R Henault. Trois ans de prison à une femme sidéenne qui a mordu une cliente dans un bar. *Le Soleil*, 12 September 2002 (www.cyberpresse.ca); La Couronne réclame quatre ans pour une prostituée sidéenne. *Canadian Press*, 2 August 2002 (www.cyberpresse.ca); AIDS patient sentenced to prison for biting woman. *Canadian Press*, 11 September 2002. (This last article reported a sentence of four years, but may have neglected to factor in the half year spent in pretrial custody, which other reports noted was factored into the judge's decision.)

¹⁰ R Elliott. Alberta: Guilty of assault causing bodily harm for biting. *Canadian HIV/AIDS Policy & Law Review* 2002; 6(3): 66.

¹¹ *R v Debnam*, [2002] ABCA 222, Court Docket No 0201-0064A.

¹² *Ibid* at paras 6-7.

¹³ Man sent to prison for hiding HIV status. *Ottawa Citizen*; 19 June 2002, B3. *R v Charbonneau* is unreported as of the date of writing.

¹⁴ The press report that is available would seem to indicate that the victim was not infected as a result of the single sexual encounter. No information is given as to whether or not the HIV-positive individual made any attempts to practise safer sex.

¹⁵ See, for example: D Wood. Kitchener, Ont., man with HIV gets 10 years for unprotected sex with 4 women. *Kitchener-Waterloo Record*; 28 June 2002. The case in question, *R v Monge*, is unreported as of the date of writing.

¹⁶ The press reports contain no information about whether or not Mr Monge attempted to practise any form of safer sex.



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BARCELONA 2002: LAW, ETHICS, AND HUMAN RIGHTS

In this special section of the *HIV/AIDS Policy & Law Review*, made possible by funding received from the Joint United Nations Programme on HIV/AIDS (UNAIDS), we reproduce the most relevant presentations on legal, ethical, and human rights issues related to HIV/AIDS given at the XIV International AIDS Conference and at the many satellite meetings, as well as selected abstracts. We did the same for Geneva98¹ and Durban 2000.² With funding from UNAIDS, this issue will be mailed to over 500 people and organizations with an interest in HIV/AIDS and human rights, particularly in developing countries, in addition to the regular distribution list. The goal is to increase access to materials on human rights, legal, and ethical issues related to HIV/AIDS for individuals and organizations worldwide; to facilitate networking among individuals and groups active in the area; and to promote policy and legal responses to HIV/AIDS that respect human rights.

This section begins with a synopsis of Track G – Advocacy and Policy. This is the conference track that included the majority of presentations on legal, ethical, and human rights issues.

¹ Geneva98: Law, ethics and human rights. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(2/3): 78-117; available at www.aidslaw.ca/Maincontent/otherdocs/Newsletter/spring99/geneva98.htm.

² Durban 2000: Law, ethics and human rights. *Canadian HIV/AIDS Policy & Law Review* 2000; 5(4): 54-117; available at www.aidslaw.ca/Maincontent/otherdocs/Newsletter/vol5no42000/durbanintro.htm.

An Advocacy and Political Conference Produces a Consensus: Effective Action Is Urgently Required

From the deep sense of frustration about the gap between what is possible and what is actually happening, a clear consensus emerged at the XIV International AIDS Conference that effective action is urgently required. This article is based on a presentation on 12 July 2002, the last day of the conference, by Terje Anderson, the rapporteur for Track G. The article presents a summary of the discussions in Track G on topics such as advocacy strategies, the use of the law, the use of a human rights framework and approach, the role of people living with HIV/AIDS, and the need to mobilize sufficient resources. The article states and then critically examines some of the consensus positions that emerged from the conference – specifically, the goal to have three million people on antiretroviral therapy by 2005; the notion that the debate around prevention versus care is over; and the idea that the key issue is no longer what we do, but how to secure the commitment and the resources to do it. The article states that the fight against HIV/AIDS must be fought on a political plane, and that it is the responsibility of everyone working in AIDS to engage our leaders. The article concludes by asking whether we really have the courage and the perseverance to turn our knowledge and our commitment into action.

At a satellite meeting just prior to the start of the conference, Justice Edwin Cameron, of the Constitutional Court of South Africa, posed a challenge to us all:

We have to ask ourselves: What is going to happen over the next eight days at this conference?

What we are going to achieve ... in relation to the awesomeness of a problem whose statistics, whose magnitude, threatens to paralyse our response? We have to ask ourselves in brute terms whether the resources required to bring us here can be justified in relation to the opportunity cost lost, the opportunity of saving a life....

Do we have sufficient outrage? Do we have sufficient anger? Do we have sufficient will to articu-

late our demands, to plan strategies, to plan campaigns that will change that world as well? ... We stand on the brink of hope. The past three and a half to four years show us what can be achieved by careful thinking, and by strategic alliances.... There is a great deal to be done.¹

The topics of Track G were advocacy and policy. However, these themes were front and centre at the entire conference, not just in Track G. From the opening speech by Dr Peter Piot, Executive Director of the Joint United Nations Programme on HIV/AIDS – which set the tone by voicing the fierce impatience shared by so many conference participants – to the direct actions by individuals challenging the people with political or economic

power, this was both an advocacy conference and a political conference. Out of this conference emerged a clear consensus – across all disciplines and backgrounds, from all parts of the world – that effective action is urgently required. We all share a deep sense of frustration about the enormous gap between what is possible and what is actually happening.

The theme of this conference was turning knowledge and commitment

We must find a way at future conferences to bring more voices of persons living with HIV/AIDS into our midst.

into action. How we will make this happen was discussed in depth in Track G. It is an honour for me to be asked to report on the discussions and outcomes of this track. I am a person living with HIV, a former injection drug user, a former sex worker, and a gay man. I am alive today largely because I had the good fortune to have been born a white man in North America. While I share much with my infected comrades, my HIV-positive friends around the world, I do not pretend to speak for the millions of people who did not have the means to attend this conference. Neither can this conference speak for them. Yet their lives depend on our ability to turn the discussions at this conference into reality. We must find a way at future conferences to bring more of their voices into our midst.

The discussions in Track G made it clear that, in order to successfully achieve policy goals, advocacy must be multi-pronged and flexible. A variety of approaches are required –

approaches such as parliamentary lobbying, community organizing, use of the courts, policy research and analysis, use of the media, capacity building, and protests. We learned that these strategies were often most successful when used in combination. For example, in the discussions on how to make drugs more affordable, strategies such as negotiating price reductions, soliciting company donations, challenging patent laws and international trade agreements, and promoting generic production, were all explored and viewed as relevant in different situations.

Case studies presented at this conference – such as South Africa's treatment-access court victory, and the use of laws to combat stigma in Namibia – demonstrated how legal approaches can be used to achieve important policy ends. Yet other studies showed that the law can be a barrier to effective HIV/AIDS policies. Papers were presented on how punitive drug laws negatively affect the spread of HIV in Argentina, Russia, and the United States; and on how the criminalization of sex work impedes prevention efforts in India and South Africa.

We learned from numerous presentations (including papers from Ethiopia, Ukraine, Brazil, Australia, and Canada) that the AIDS movement has become adept at operating within a human rights framework, and at using that framework to advance successful care, treatment, prevention, and research programs. But we also learned that the use of this framework is far from universal.

The use of a human rights-based approach continues to be codified in international and professional standards – a good example is the International Labour Organization's *Code of Practice on HIV/AIDS and the World of Work*² – but case studies

from every region of the world showed that formal adoption of these standards does not guarantee that they will actually be implemented.

We heard at this conference, even more than at past conferences, about the critical role that people living with HIV/AIDS play in the fight. We saw clear examples – from Chile, Ukraine, Thailand, Indonesia, Kenya, Honduras, and elsewhere – of leadership by people with HIV/AIDS in the creation of policy and legislation. We learned that the involvement of these people generates opportunities and also creates challenges both for themselves and for the institutions with which they are involved. We also learned that the meaningful involvement of people with HIV/AIDS requires action and commitment, not just ideological lip service.

There was considerable emphasis on the need to mobilize sufficient resources to mount an effective response to the epidemic. Studies presented at this conference demonstrated wide variations among industrialized nations in terms of how much they were prepared to spend on domestic and global AIDS spending; and wide variations in health spending in developing and middle-income countries. The difficulties of conducting sound cost-benefit studies, and of estimating the costs of much-needed programs, are major barriers to securing enhanced resources.

We learned how information gathering tools – such as the HIV human rights audit in Australia,³ and the rapid policy assessment tool for measuring drug and harm-reduction policies in Eastern Europe and the former Soviet Union – have been used to inform policy analysis and advocacy.

At the Barcelona Conference, some consensus policy positions emerged – ie, positions repeated often enough in

oral sessions, plenaries, policy speeches, hallway conversations, and media coverage, that they became accepted as the shared view of the entire AIDS community. The mantra of three million people in the South receiving antiretroviral (ARV) therapy by 2005 has been repeated so widely that it has become viewed as a goal by many. Yet many questions were raised about this. Which three million? Where? Who will decide? Who will be left out? If three million is possible, why not six, nine, twelve, or twenty-four million? How does the three-million target relate to the number of people who actually need ARVs? Has anyone asked the people who will not receive treatment if they accept this “consensus” goal?

We heard repeatedly that the debate about prevention versus care is over. Yet, while the debate may be over in the minds of the opinion leaders at this conference, various presentations suggested that the debate is still being played out – and may continue to be played out – in resource-allocation decisions made by the Global Fund to Fight AIDS, Tuberculosis and Malaria, by aid agencies, and by national governments.

There was a consensus in Barcelona that the key issue is no longer what to do, but rather how to secure the commitment and the resources to scale up models that we already know are working. At the same time, presentations at the conference demonstrated that there is still much to learn about the best ways to deliver prevention and care.

There was a heightened recognition at this conference of the extent to which marginalization and stigma continue to define and shape this epidemic. There was an increased focus on the importance of human rights

approaches. The right of people with HIV/AIDS to travel freely re-emerged as an issue.

It remains unclear whether scientists, doctors, people with HIV/AIDS, NGOs, service providers, and other relevant players are willing to take the risks associated with entering the political arena.

Finally, this conference has clearly shown, more than ever before, that this fight is being fought – and must be fought – on a political plane. It has shown that the fight requires engaged political leadership, and that it is the responsibility of everyone working in AIDS to engage our leaders when they do not seem to be paying atten-

tion. Yet it remains unclear whether scientists, doctors, people with HIV/AIDS, NGOs, service providers, and other relevant players are truly willing to take the risks associated with entering the political arena. It may be safe to give advocacy speeches and to blow whistles among like-minded people at an AIDS conference, but how many people are willing to do these things when it could mean loss of government funding, loss of access to decision-makers, unemployment, or social isolation?

What we do while here in the safe bubble of an AIDS conference may bear little resemblance to what happens when we leave. Will we have the courage and perseverance to really turn knowledge and commitment into action? Or will it become business as usual for another two years? Can those whose voices are not here really count on us to make good on our promises, or will millions die because of our inability to take action?

As Thucydides once said: “Justice will come when those who are not injured are as indignant as those who are.” As we leave Barcelona, we must leave more indignant, more angry, more impatient, and more ready to act than when we arrived. Only if we do that can this conference meet the test that Justice Cameron laid out at the beginning of the week.

– Terje Anderson

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¹ Justice E Cameron. Opening Commentary at *Putting Third First: Vaccines, Access to Treatment and the Law*, a satellite meeting held on 5 July 2002 in Barcelona. The Opening Commentary is included in the proceedings of the satellite meeting, which are available on the website of the Legal Network at www.aidslaw.ca/barcelona2002/satellite_proceedings.pdf.

² Available on the website of the ILO via www.ilo.org/.

³ See “Abstract G5560: Auditing Human Rights in the Context of HIV/AIDS,” in the article entitled “Barcelona 2002: Abstracts on Legal, Ethical, and Human Rights Issues” at the end of this special section of the *Review*.

Global Battle Cry: Health is a Right, Not a Commodity

Health is a fundamental right, not a commodity to be sold at a profit, argues Irene Fernandez in the second Jonathan Mann Memorial Lecture delivered on 8 July 2002 to the XIV International AIDS Conference in Barcelona. Ms Fernandez had to obtain a special permit from the Malaysian government to attend the Conference because she is on trial for having publicly released information about abuse, torture, illness, corruption, and death in Malaysian detention camps for migrants. This article, based on Ms Fernandez’ presentation, describes how the policies of the rich world have failed the poor world. According to Ms Fernandez, the policies of globalization and privatization of health care have hindered the ability of developing countries to respond to the HIV/AIDS epidemic. The article decries the hypocrisy of the industrialized nations in increasing subsidies to farmers while demanding that the developing world open its doors to Western goods. It points out that the rich nations have failed to live up their foreign aid commitments. The article concludes that these commitments – and the other promises made in the last few years, such as those in the United Nations’ Declaration of Commitment on HIV/AIDS – can only become a reality if they are translated into action.

It is indeed an honour and privilege for me to deliver the second Jonathan Mann Memorial Lecture at a confer-

ence whose theme is “Knowledge and Commitment for Action.” Jonathan Mann dedicated his life to building a

global response to the AIDS pandemic. He was a living example of how to translate knowledge into commitment

and action. Today, more than ever, we are challenged to strengthen, deepen, and consolidate what Mann left behind.

The significance and realization of Jonathan Mann's work culminated when he became intensely involved with the African communities who were suffering and dying from AIDS. Mann emphasized the links between human rights and vulnerability to HIV/AIDS. He wrote, "In each society, those people who were marginalized, stigmatized and discriminated against – before HIV/AIDS arrived – have become over time those at highest risk of HIV infection."¹

This is as true today as it was when he wrote those words. Today, we see growing inequalities and a world that is now divided into two different worlds. One world, where less than one-third of the people live, is rich, powerful, and united. In this world, last year, 500,000 people were on antiretroviral drugs and 25,000 people died of AIDS. In this world, there are resources and access to treatment.

The other world, where more than two-thirds of the people live, is poor, in debt, divided, controlled, and in despair. In this world, 230,000 people are on antiretroviral drugs. Half of them are from Latin America, mostly from Brazil. Only 30,000 out of almost 30 million people now living with the death sentence of AIDS in sub-Saharan Africa are being given the drugs. Last year, 2.2 million people died of AIDS in Africa alone. The disparity is more than alarming – it is criminal. The highly populated countries of Asia face one of the greatest challenges – and risks – in the global battle against HIV/AIDS. With such large populations – China and India account for one-third of the world's

people and Indonesia is the world's fourth most populous nation – even extremely low rates of infection can be devastating.

In June 2002, the Joint United Nations Programme on HIV/AIDS (UNAIDS) published a separate report on HIV/AIDS in China,² warning that if no effort is made to step up prevention and education, the number of HIV-infected people in that country could jump from current estimates of 1.5 million to 10 million by 2010. That would put China "on the verge of a catastrophe that could result in unimaginable suffering, economic loss and social devastation."³ The Chinese government rejected the report, calling its conclusions and predictions inaccurate. The report did not criticize the Chinese government, but lamented the lack of action on the provincial level, where much of the funding and decision-making occurs. It is this type of denial that makes many countries in Asia a ticking time bomb.

Destructive Policies

The inequalities and disparities are further fuelled by increasing stigmatization, discrimination, and growing xenophobia in the developed world. This is evident in the new forms of harsh and racist policies against migrants, refugees, and displaced persons. Canada, a country that had a reputation for respecting the rights of people, today imposes mandatory HIV testing on all potential immigrants. Migrant workers going to various receiving countries are required to undergo medical tests with absolutely no counselling or free consent. If found HIV-positive, they are immediately deported. In many cases, the workers are not even told that they are positive. On returning to their communities, they are further

stigmatized and ostracized, and sometimes even treated like criminals.

Existing inequalities and disparities are further fuelled by increasing stigmatization, discrimination, and growing xenophobia in the developed world.

It is well known that poverty creates high vulnerability to AIDS. Yet at the last World Food Summit, held in Rome in June 2002, governments stuck with the same plan that has increased world hunger since 1996. Their plan of action compounds the error of "more of the same failed medicine" with destructive prescriptions of trade liberalization, privatization, and commodification of basic needs and resources. Parallel to this, we witness the increasingly brutal repression of social movements and human rights initiatives that try to resist this new world order. The mantra of the G8 patricians is that trade will set us free. But how can this be true when the United States spends US\$190 billion in agricultural subsidies for its farmers, and the European Union spends US\$160 billion to protect its farm industry? Meanwhile, governments in the South are required to lift their subsidies to farmers. This is the contradiction and hypocrisy of the rich world.

The International Monetary Fund (IMF) and the World Bank have used structural adjustment programs to force nations to privatize their health-care services, thereby creating a greater role for market forces in the production and distribution of such

services. The result is that health care has been converted into a lucrative trade in people's health. People who need to access health care now have to purchase it through medical insurance. But the insurance industry will not offer insurance to a person who is HIV-positive. This not only marginalizes people living with AIDS; it also denies them their right to treatment.

As a result of the globalization of drug patents and pricing, and the privatization of health-care services, governments no longer have control over the health care of their people. Instead, the power is vested in the hands of powerful drug companies and the insurance industry. When health-care services are privatized, health care is compromised. Without adequate health care, we end up with deteriorating health and environmental conditions that are conducive to outbreaks of infectious diseases. By turning health into a commodity for profit, we have created a very fertile

By turning health into a commodity for profit, we have created a very fertile environment for the AIDS virus to multiply.

environment for the AIDS virus to multiply.

The poor are spending every penny they have on the sick and the dying. In Rwanda, private, out-of-pocket spending accounted for 93 percent of total HIV/AIDS spending in 1998-1999. Only seven percent came from government and donors.⁴ Such high dependence on out-of-

pocket spending, especially by the poor, is of grave concern, particularly since it is the wage earners who are dying. Last year alone, one million children in Africa lost their teachers to AIDS.

Lack of Resources and Commitment

Today, Africans are leaders in managing care, building supportive communities, and developing creative prevention programs. It is not a lack of knowledge that is the bottleneck. It is a lack of resources. The shortfall in resources stems from a lack of global commitment. When member states of the United Nations adopted the Declaration of Commitment on HIV/AIDS in 2001, they calculated that US\$7 to 10 billion a year would be needed to fight HIV/AIDS.⁵ But so far only a little more than \$2 billion has been committed. As Peter Piot, Executive Director of UNAIDS said: "We haven't reached the peak of the AIDS epidemic yet.... The money that is needed to be spent is not asking for the moon. By any standards that are used for breaches of security, that's peanuts."⁶

The G8 countries are continuously in default. They have not met the aid targets they set as far back as 1970. The member states of the Organization for Economic Cooperation and Development (OECD) pledged to devote 0.7 percent of GDP to foreign aid. However, current official development assistance is only 0.22 percent of GDP, which amounts to US\$53 billion in assistance each year for the entire developing world. At 0.7 percent of GDP, development assistance would amount to US\$175 billion today and US\$200 billion by 2005.

The United States is currently contributing US\$10 billion a year, or

0.15 percent of GDP. At the Financing for Development conference in Monterey, Mexico in March

If the G8 countries had lived up to their commitments on foreign aid, we could have saved millions of lives and reversed the pandemic.

2002, the US said that it would increase foreign aid by US\$5 billion a year by 2006. Even with this increase, the US will reach only one-fifth of the 0.7 percent target. The European Union committed another US\$7 billion a year at Monterey, but that only brings it halfway to the 0.7 percent target. Canada has said it would increase its official development assistance by eight percent a year, but it made that pledge only after the government had severely slashed the budget of the Canadian International Development Agency. If the G8 countries had lived up to their commitment, we could have saved millions of lives and reversed the pandemic.

It is not just the lack of commitment that is problematic, but also the conditions that come with the aid. For example, the New Partnership for African Development (NEPAD)⁷ makes development a pipe dream. Under NEPAD, Africa has to live up to the same type of conditions and structural adjustment programs that have caused the catastrophe we know today. Furthermore, NEPAD hardly mentions AIDS. If we do not deal with AIDS in Africa, there will be absolutely no development. The three key indicators of development are

access to food, education, and health. The pandemic is destroying all three. In fact, there will be negative growth if the pandemic is not arrested.

Political will at the global level can be formidable. Scores of billions of dollars were mobilized overnight to avenge the horrendous deaths of three thousand people in the United States on September 11th. The war on terrorism continues with even greater zeal. Why has so much value been accorded to those three thousand lives, while there is so little thought and political will for the millions dying of AIDS? Why is the war against terrorism so sacrosanct, but the war against AIDS so weak?

A Paradigm Shift Is Needed

To win the war against AIDS, we need a paradigm shift. Health must be recognized as a fundamental right, not as a commodity to be traded for profit. When human rights are denied, vulnerability to AIDS increases. A rights-based approach means we must find ways to make

Why is the war against terrorism so sacrosanct, but the war against AIDS so weak?

accessible to the poor and those in need what is within the reach of the affluent.

There has been some progress.

- The court victory of the South African government over drug companies two years ago has raised hopes that poor countries will be able to buy quantities of cheap drugs.

- In the wake of the South African court case, UNAIDS set up a scheme to supply discounted drugs to African countries.
- Brazil decided to establish a legal right to free medication and has provided treatment and care to more than 100,000 people living with HIV/AIDS. As a result, the number of AIDS deaths in Brazil in 2000 was a third of what it was in 1996. Similar legislation-led drug-access models are being pursued across Central and South America.

Thus, a new paradigm in access to care is beginning to take effect, and long-standing global inequities are being challenged. From disputes before the World Trade Organization to court cases in South Africa, debate in relation to essential medicines has been resolved in favour of lowering trade barriers to access. The principle of preferential pricing for HIV drugs for low- and middle-income countries has been largely accepted in the pharmaceutical industry. Prices have begun to drop. The right of countries to invoke compulsory or voluntary licensing arrangements on patented drugs and medications was affirmed clearly at the World Trade Organization meeting in Doha, Qatar, in late 2001.⁸

But this is not enough. We need to go further. We need to attack the root causes of the denial of treatment. Unless and until health is recognized as a fundamental right, all our interventions will become only band-aid solutions. We need to take health out of the hands of the World Trade Organization. Health cannot be seen as a commodity anymore. Health care must be available for all people, especially the poor. Governments, not transnational drug corporations, must be responsible for delivering

effective health care and providing access to treatment. Programs must be guided by human rights principles that protect the dignity of people

A rights-based approach means we must find ways to make accessible to the poor and those in need what is within the reach of the affluent.

infected and affected by HIV/AIDS. All governments and international institutions have the obligation to respect, protect, and promote these rights.

The international human rights framework provides a solid basis for individuals and organizations to demand these rights. The right to health has been officially recognized in several international conventions and has been well articulated by the United Nations Committee on Economic, Social and Cultural Rights.⁹ The integral link between HIV/AIDS and human rights was recognized at the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) in 2001.¹⁰ Two resolutions of the United Nations Commission on Human Rights have recognized that access to medication in the context of epidemics such as HIV/AIDS is fundamental to achieving the full realization of the right to the highest attainable standard of physical and mental health. The resolutions call upon states to pursue policies that promote the availability of HIV/AIDS-related medications in sufficient quantities and in ways that make them accessible to all.¹¹

Conclusion

The Millennium Development Goals, arising from the UN Millennium Summit of September 2000, include a commitment to halt and begin to reverse the global spread of AIDS by 2015. They also include the following goals: to halve global poverty; to ensure primary-school education for all; to promote gender equality and empower women; and to reduce child mortality while improving maternal health. This total package is integral to success in alleviating the impact of AIDS.¹²

But whether it be the millennium goals, or UNGASS goals, or the Global Fund goals, they can only become a reality if there is commitment to translate goals into action. It is up to each of us to make this commitment. A dear friend of mine, Jonathan de Vera, died of AIDS in 2002. When he was first informed of the results of his HIV test, said: “I

was shocked. I felt weak ... I never knew how I managed to get home. [Then] I finally realized that life was beautiful and should never be taken for granted. That is a gift from God.” Yes, life is a gift from God. It must be protected at all costs and given the highest value. I hope that everyone affected by AIDS can live their lives to their fullest potential. Let not AIDS rob us of this opportunity.

– Irene Fernandez

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¹ From an address that Jonathan Mann gave to the 2nd International Conference on Home and Community Care for People Living with HIV and AIDS, Montréal, Canada, 24-27 May 1995.

² UN Theme Group in China. HIV/AIDS: China's Titanic Peril: 2001 Update of the AIDS Situation and Needs Assessment Report, June 2002. Available on the website of UNAIDS at www.unaids.org/whatsnew/newadds/AIDSchina2001update.pdf.

³ Ibid at 9.

⁴ UNAIDS. Meeting the Need. Fact Sheet 2002. Available on the website of UNAIDS at www.unaids.org/barcelona/presskit/factsheets/FSresources_en.doc.

⁵ United Nations General Assembly. Declaration of Commitment on HIV/AIDS. Paragraph 80. A copy of the Declaration is available on the website of UNAIDS via www.unaids.org/UNGASS/index.html.

⁶ From an interview Dr Piot did with Reuters, published 2 July 2002. Available on the website of www.millennium2.org at www.millennium2.org/whatsnew/newarc07.htm.

⁷ For information on NEPAD, visit the NEPAD website at www.nepad.org.

⁸ The Doha Declaration. Available on the website of the WTO via www.wto.org.

⁹ UN Committee on Economic, Social and Cultural Rights. General Comment 14: The right to the highest attainable standard of health. 4 July 2000, UN Doc E/C.12/2000/4, CESCR. Available on the website of the United Nations High Commissioner for Human Rights via www.unhchr.ch.

¹⁰ Supra, note 5 at Paragraph 16.

¹¹ UN Commission on Human Rights. Resolutions 2001/33 (23 April 2001) and 2002/32 (22 April 2002). Available on the website of the UN High Commissioner for Human Rights via www.unhchr.ch.

¹² Information on the Millennium Development Goals is available at www.developmentgoals.org.

The Need for Harm-Reduction Approaches in Eastern Europe and the Former Soviet Union

In a region where HIV is spread primarily by injection drug use, harm-reduction strategies must be the mainstay of prevention efforts. In her plenary presentation to the XIV International Conference on AIDS on 9 July 2002, Kasia Malinowska-Sempruch asserts that if the world does not turn its attention to the emerging and exploding epidemic in Eastern Europe and the former Soviet Union, the region will suffer the same fate as Africa. The presentation explains that while their economies continue to struggle, the countries in the region have seen their public health systems crumble in the face of the twin health crises of injection drug use and HIV infection. The presentation demonstrates how current repressive laws and practices with respect to drug use serve only to fuel the epidemic. It describes harm-reduction approaches (such as needle exchanges and drug-treatment programs) and provides examples of how NGOs in the region have been attempting to implement such approaches, often with little or no support from governments. Finally, the presentation outlines other measures required to respond to the epidemic in the region, including ensuring that people infected with HIV can access care, treatment, and support services.

People working in HIV in Eastern Europe and the former Soviet Union have been talking for over a decade

about the social, economic, and human factors that make countries in this region susceptible to HIV. In 2002

we no longer speak of what may be: HIV and AIDS have arrived and are causing devastation in this region, just

as they do everywhere else. For three years in a row, UNAIDS has reported that HIV is growing faster in Eastern Europe and the former Soviet Union than anywhere in the world. Today there are almost 200,000 officially registered HIV infections in Russia. The real numbers are estimated to be much higher – at least one million. Ninety percent of them are injection drug users. The situation is equally dire in neighbouring Ukraine, where close to one percent of the population is estimated to have HIV; again, the majority are injection drug users.

As a native of Poland, not only am I terrified by the rapidly growing HIV epidemic but I am also frustrated and angry. The world celebrated with us when the Berlin Wall fell and then left us alone to deal with the consequences. Although many countries in our region embraced democracy over the past decade, the promised economic benefits have yet to arrive. We are richer in terms of human rights and some essential personal freedoms, but we are poorer in many other ways.

From the Czech Republic to Uzbekistan, as the economies of the region continue to struggle, the public health systems are crumbling. Absolute poverty levels are up while living standards and life expectancies are falling. Per capita gross domestic product (GDP) in Russia is less than US\$5000 a year. This is lower than the GDP in countries that have long been considered less developed, such as Brazil and Thailand. As bad as the economic situation is in Russia, it is even worse in Ukraine and Central Asia, where a growing number of people are forced to get by on less than US\$2 a day. In Central Asia, some women are trafficking drugs to buy schoolbooks and shoes for their children. The sex-work industry is

rapidly expanding throughout the region.

Two Emerging Health Crises

And now the countries of this region are facing two linked health crises that threaten to dwarf all other issues: soaring injection drug use and HIV infections. If the world is unable or unwilling to turn its attention to this region, and to offer help in dealing with this looming disaster, the consequences will be horrific.

This may sound familiar. Activists sounded similar alarms more than a decade ago in Africa as the AIDS epidemic swept large parts of the continent. For a variety of reasons, governments, international organizations, and pharmaceutical companies preferred to ignore the imminent African AIDS epidemic, even after the first signs of the catastrophe appeared. Before long, it was impos-

If the world is unable or unwilling to turn its attention to Eastern Europe and the former Soviet Union, the consequences will be horrific.

sible to ignore – the continent had already buried millions of people, and tens of millions more had been infected. This is not only an economic and social disaster, but also a moral one. No matter how much attention donor nations give to Africa now, it will never be forgotten that the world fell brutally short of meeting its humanitarian obligations. As we consider strategies for Eastern

Europe and the former Soviet Union, we have an opportunity to apply the lessons learned so tragically in other parts of the world.

In Eastern Europe and the former Soviet Union, HIV is spread primarily through injection drug use. Economic despair, social dislocation, and easy access to heroin and other opiates have all contributed to an explosion of drug use. Already on the margins of society, injection drug users receive little or no sympathy from the general population. There is an illusion that drug users are somehow separate and isolated, and that illness and death in their ranks have no impact on the fabric of society as a whole.

There have been instances of parents in Central Asia watching their children die of overdoses, too afraid of police harassment to bring them to a hospital. This fear and silence – which authorities have so far failed to adequately counter – breeds HIV and underscores the intimate relationship between drug policies and AIDS policies.

Reflex Reactions

In countries that are experiencing a rapid increase in drug use, often the reflex reaction is to become tougher on drug users. Locking drug users up in prisons is not a solution; it only makes things worse by driving users underground and making them less likely to access what few services do exist for them.

The United States, with its failed war on drugs, is an example of the futility of focusing on incarceration as a strategy. Aggressive enforcement of zero-tolerance laws has not reduced addiction rates; instead, it has simply made the US the world's leading incarcerator. Rather than allocate resources to harm reduction

and drug treatment, US policymakers spend billions of dollars on new prisons.

By favoring confinement over treatment in Eastern Europe and the former Soviet Union, authorities are condemning drug users to overcrowded prisons where needles are shared and HIV rates are surging at an even faster rate than in the population at large. In Russia alone, more than 33,000 prisoners have tested HIV-positive. A large percentage of these prisoners are or will be infected with tuberculosis (TB), which has itself reached epidemic levels in the

In the prison system, with its high rates of HIV infection and TB, sentences for even minor offences often become death sentences.

former Soviet Union. TB is now the most common killer of HIV-infected people in the region. In the prison system, more than 30 percent of people with TB have a multi-drug-resistant strain of the disease. Prison sentences, even for minor offences, often become death sentences.

Halting the spread of HIV among drug users requires entirely new ways of thinking. National and local governments must implement flexible and caring health policies that focus on helping drug users, not punishing them. More important, we need to look at our own national prejudices, our own professional stereotypes, and our own personal judgments that are standing in the

way of providing those in need with immediate assistance.

Making Harm Reduction Work

We know what works. At the Open Society Institute, we strongly believe in the concept of harm reduction as the most humane and realistic way to stem the spread of HIV among drug users. Harm reduction means meeting drug users on their own ground, and providing access in a non-judgmental manner to ways in which they can reduce the risk that they will contract HIV or other serious conditions.

One key element of most harm-reduction programs is needle exchange. Hundreds of studies around the world have shown that providing injection drug users with access to clean needles greatly reduces needle-sharing and, thus, HIV infection. The World Health Organization, the American Medical Association, UNAIDS, and many others consider the provision of clean syringes to be an effective and necessary method of preventing HIV transmission among injection drug users.

Treatment programs that offer methadone and other substitution therapies are another vital part of harm-reduction efforts. Unfortunately, rigid and repressive drug policies in many countries mean that drug treatment programs are few and far between. This situation is unethical.

Even so, harm reduction is not an unknown concept in Eastern Europe and the former Soviet Union. Small NGOs have set up shop to provide needle exchanges in nearly every country, with or without the acceptance or support of governments. There are committed people in the

region who have long dared to defy conventional wisdom and who treat drug users as human beings deserving of as much care, education, and assistance as other members of society. In Poland, early in the epidemic, a doctor spoke publicly about the need for methadone maintenance programs to be implemented as a front-line approach to the drug-use epidemic. Most public health officials in my country now accept such programs as vital.

In Bulgaria, a small group of volunteers drive a battered bus into isolated Roma communities and offer clean needles to injection drug users who have faced more discrimination and stigma than most of us can possibly imagine. In Ukrainian cities, there are former drug users who risk entrapment and arrest by going directly to shooting galleries and handing out information and offers of support to homeless youth who are desperate and malnourished. In St Petersburg, elderly women can get their blood pressure checked in a mobile clinic where drug users exchange needles. There are mayors and public health officials across the region who do their best to provide free space for drop-in centres, and there are physicians and nurses who take off their white coats and transform themselves into outreach workers.

Such local efforts are the cornerstone on which harm reduction should be built. But those harm-reduction services that do exist have limited resources and risk being swamped as the number of clients continues to climb.

From an intervention standpoint, needle exchange is easy to do – easier, certainly, than many other prevention programs. We know from years

of experience with behaviour-change interventions in the area of sexual health that there is a long list of rea-

There are physicians and nurses who take off their white coats and transform themselves into outreach workers.

sons why people do not want to use condoms – for example: “I don’t need to with my wife;” “he’ll think I’m a slut;” “they reduce sensation;” “it’s against my religion;” and “stopping to put them on breaks the mood.” Drug users would come up with a very different list of reasons for not using clean needles. These would have little to do with individual choice, but might include: “syringes are not available;” “I’m afraid of being stopped by the police outside the pharmacy;” and “walking into a needle exchange may cause my children to be taken away.”

When I visit programs that we support throughout the region, I am always amazed that people are willing and motivated to travel across town, often a few times a week, in minus-20-degree weather, for clean needles, for a warm cup of tea, and for a visit with a nurse who can look at an abscess without delivering a sermon. If a harm-reduction program is well designed and if it is user friendly, well located, and committed, it can reach large numbers of people. And there is no reason for people not to use clean needles. If every drug user were provided with clean syringes and needles, the overwhelming majority would use them.

Other Measures

Harm reduction makes a huge difference and saves countless lives, but we need to go even further. We must make people feel safe and respected, so that they will want to be tested to find out if they are HIV-positive. We must be able to demonstrate to people that they will benefit from being tested. The entire system of HIV testing in the region, still based on the Soviet model, needs to be revamped.

We must change the way we think of people living with HIV. This is much harder than it should be because of lingering stigma and shame. For example, the former Soviet Union is a place where doctors were required by law to report to the police the names of patients taking narcotics. This is no longer necessary under current law, but since we are creatures of habit, this type of dialogue between police and physicians continues.

We must make people living with HIV feel that they are part of the prevention effort so that they become active partners in keeping others free of infection. We also need to ensure that people infected with HIV can access social and medical services. It is not reasonable to expect that people living in the former Soviet Union will have easy access to sophisticated antiretroviral combinations in the near term. But there is a lot that can be done now, such as providing TB treatment and prophylaxis for opportunistic infections.

Unfortunately, there are few, if any, HIV treatment options available to HIV-infected drug users. When they turn to doctors for help, often the doors are slammed in their faces. A survey by the Central and Eastern European Harm Reduction Network found that drug users are often

placed last on the list of people in line for antiretrovirals, are required to stop methadone in order to gain access to HIV treatment, or are denied antiretrovirals altogether.

Offensive assumptions and stereotypes have been used before to justify denial of HIV treatment to other groups. We have been told that gay men are self-destructive and not interested in taking care of their health. We have been told that Africans cannot tell time, and are therefore unable to comply with complicated regimens. Now we are told that drug users, by their very nature, are non-compliant and not worth treating.

AIDS service providers and policymakers must change the condescending way they treat drug users. They must stop treating them as though they are incapable of making informed decisions about their health. Using non-compliance as a reason for denial of treatment is unfair and unproductive, and it ignores the real problem. If there is

If there is one thing that drug users know well, it is how to take drugs.

one thing that drug users know well, it is how to take drugs. Furthermore, if providers do not offer treatment in a way that recognizes the realities of the lives of drug users, then it is hardly surprising that the treatment regimen cannot be followed. Our work in the region has shown us that, with appropriate support, a drug user is as likely to be compliant as any other person with HIV.

Violence at the hands of police, denial of public services, imprisonment that destroys health and breaks the spirit, so-called “drug treatment” that humiliates clients and their families – these are all human rights abuses experienced by drug users. Not only do these abuses make for a repressive society; they also feed the HIV epidemic.

It is not a question of not having enough resources and know-how. Russians have orbited the moon and have built tens of thousands of nuclear warheads. If they could accomplish these two expensive and complex tasks, there is no reason

why they cannot produce the generic antiretrovirals that are needed right now. Are not 200,000 HIV infections within three years reason enough to spur the development of an aggressive domestic treatment plan?

My father was sentenced to life in prison at age 18 for political activity. He spent 12 years in prison, and died before Poland became a truly independent country again in the late 1980s. There are hundreds of thousands of men and women who, like my father, sacrificed their lives opposing communism. They did not do this so they could now watch their children, or their children’s children,

or their neighbour’s children, be locked up in prison for drug use or die of a drug overdose or AIDS.

Repressive drug policies fuel the HIV epidemic.

Needle exchange and substitution therapy save lives.

Drug users care about their health and must be offered HIV treatment.

– *Kasia Malinowska-Sempruch*

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Using the Law to Improve Access to Treatments

The XIII International AIDS Conference in Durban, South Africa in July 2000 focused worldwide attention on the problem of accessing treatments in developing countries. In the interim, thanks to the work of activists – from demonstrations to court cases, and from acts of public courage by people living with HIV/AIDS to ongoing lobbying of politicians and trade negotiators – some very significant developments have occurred. But the reality is that the vast majority of people living with HIV/AIDS still lack access to affordable, quality medicines. This article, a summary of a paper¹ presented at “Putting Third First: Vaccines, Access to Treatments and the Law,” a satellite meeting held at Barcelona on 5 July 2002 and organized by the Canadian HIV/AIDS Legal Network, the AIDS Law Project, South Africa, and the Lawyers Collective HIV/AIDS Unit, India, explores three approaches for improving access. In the first part, Richard Elliott provides an overview of the state of the right to health as embodied in international human rights law; comments on the experience to date in litigating claims to the right to health; and identifies potential strategies activists can adopt to advance recognition of the right to health. In the second part, Sharan Parmar and Vivek Divan describe price-control and drug-financing mechanisms used by industrialized countries to increase the affordability of medicines; and discuss how some of these mechanisms could be adapted for use in developing countries. Finally, Jonathan Berger describes the use of litigation in the courts by the Treatment Action Campaign in South Africa.

Part I: The Human Right to Health

Human rights norms as stated in international and domestic law have an important symbolic value – as precepts that governments have recognized, thereby giving them some rhetorical weight in efforts to shape public policy, and as moral claims that can inspire individuals and communities. They also have a more tangible legal value – given the right configuration of political will, public opinion, and judicial resolve, they can be legally enforced and thus generate real benefits for people.

The Right to Health in International Law

The “enjoyment of the highest attainable standard of health” has been recognized as “one of the fundamental rights of every human being” by the international community ever since the

adoption of the Constitution of the World Health Organization in 1945.² The right to health is embodied in one form or another in a number of international treaties and declarations. For example:

- The Charter of the United Nations³ imposes a treaty obligation on UN member states to “take joint and separate action” for the achievement of “higher standards of living ... and conditions of economic and social progress and development;” “solutions of international ... health problems;” and “universal respect for, and observance of, human rights and fundamental freedoms for all.”⁴
- The Universal Declaration of Human Rights (UDHR) states that “everyone has a right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing, and medical care and necessary social services;”⁵ and the right “to share in scientific advancement and its benefits.”⁶
- The International Covenant on Economic, Social and Cultural Rights (ICESCR) “recognizes the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.”⁷
- The International Covenant on Civil and Political Rights (ICCPR) recognizes the rights to life and to security of the person.⁸

Other conventions within the UN system further elaborate the right to health for particular populations. Various regional human rights instruments also recognize the right to health.

However, to be able to enforce this right, one has to first determine its

content. The most detailed articulation of the content of the right to health in international law is found in General Comment 14 of the UN Committee on Economic, Social and Cultural Rights. The Committee states that the right to health must be understood as a right to the enjoyment of a variety of facilities, goods, services, and conditions necessary for the realization of the highest attainable standard of health. It identifies four interrelated and essential elements of the right to health: availability, accessibility (including affordability), acceptability, and quality.⁹

The Committee observes that, as with all human rights, the right to health imposes on states obligations to *respect, protect, and fulfil* the right. The obligation to *respect* requires states to refrain from interfering directly or indirectly with the enjoyment of the right to health. The obligation to *protect* requires states to take measures that prevent third parties from interfering with the right to health; and to adopt legislation or to take other measures ensuring equal access to health services. Finally, the obligation to *fulfil* requires states to adopt appropriate legislative, administrative, budgetary, judicial, promotional, and other measures toward the full realization of the right to health. This includes the adoption of a national health policy with a detailed plan for realizing the right to health; positive measures to enable individuals and communities to enjoy the right to health; and actions that create, maintain, and restore the health of the population.¹⁰

Recently, there have been developments concerning access to medicines as a component of the right to health. The International Guidelines on HIV/AIDS and Human Rights were adopted by the UN Office of the High

Commissioner of Human Rights and the Joint UN Programme on HIV/AIDS (UNAIDS) in 1998.¹¹ Guideline 6 says that “States should enact legislation to provide for the regulation of HIV-related goods, services and information, so as to ensure widespread availability of qualitative prevention measures, adequate HIV prevention and care information and safe and effective medication at an affordable price.” In 2002, this

The right to health imposes on states obligations to respect, protect and fulfil the right.

Guideline was updated to reflect recent developments in international law and policy regarding access to treatment.¹²

The UN Commission on Human Rights has now adopted, at successive sessions, two resolutions declaring that “access to medication in the context of pandemics such as HIV/AIDS is one fundamental element” for realizing the right to health.¹³ The resolutions further call upon states “to pursue policies which would promote the availability and affordability of medicines and medical technologies” and “to ensure that the application of international agreements is supportive of public health policies promoting broad access to safe, effective and affordable pharmaceuticals and technologies.”

In November 2001, the 4th Ministerial Conference of the World Trade Organization (WTO) adopted the Doha Declaration.¹⁴ The Declaration states that the WTO’s

agreement on patents, the Agreement on Trade-Related Aspects of Intellectual Property Rights (the TRIPS Agreement) “does not and should not prevent [WTO] Members from taking measures to protect public health;” and “can and should be interpreted in a manner supportive of WTO Members’ right to protect public health and, in particular, to promote access to medicines for all.”

Litigating the Right to Health

Advancing the right to health as a notionally binding norm in international law is important, but this “of course, can only go a limited distance in achieving the desired objectives of social justice.... [I]t will only be through increasing the incorporation of international norms within national legal structures, coupled with the amplification of efforts towards expanding the justiciability and enforcement of socio-economic standards at the local level that violations of these rights can be effectively combatted.”¹⁵

Access to medication in the context of pandemics such as HIV/AIDS is one fundamental element for realizing the right to health.

Litigation aimed at improving access to treatment for people living with HIV/AIDS has generally rested on two kinds of claims: (a) challenges to discrimination in access to health care, and (b) claims to an independent right to health.

A common example of a claim based on discrimination is a proceeding against a health-care professional for refusing to treat people because of their HIV-positive status. There have been many such cases, in both developed and developing countries, reflecting both the prevalence of such discrimination and the fact that the domestic law of most countries contains enforceable provisions prohibiting such discrimination.

The second category of cases consists of those claiming an independent right to health (or some similar right) that imposes a positive obligation on government to provide health-care goods or services (or at least to ensure or facilitate access to such goods and services). Efforts to enforce health-related entitlements through legal action have been relatively rare – frequently hindered by the difficulty in enforcing international law norms; the absence of domestic law provisions that can translate a right recognized in international law into entitlements enforceable by domestic courts; and ideological hostility or indifference on the part of governments and many judges to recognize any enforceable “right” to health. Nonetheless, there have been some efforts, putting the lie to the claim that such rights are not justiciable.

Interestingly, the most successful litigation has come from activists in developing countries and much of it has occurred very recently, in the context of efforts to use the courts to gain access to medicines for people living with HIV/AIDS.¹⁶ Latin American activists have been particularly successful with such strategies (although limits on health budgets and bureaucratic inefficiencies continue to remain a common problem that often frustrates proper compli-

ance with court orders obtained).¹⁷ Not surprisingly, such efforts have been most successful where the right

Making access to treatment a reality for the millions of people living with HIV/AIDS who do not yet have it requires activism on many fronts.

to health finds some purchase in domestic constitutional law – the strongest possible basis for enforcing a legal claim.

Strategies for Advancing the Right to Health

Making access to treatment a reality for the millions of people living with HIV/AIDS who do not yet have it obviously requires activism on many fronts. The following is a list of possible advocacy strategies aimed at improving access by advancing the recognition of the right to health in international or domestic law. The list is provided to generate discussion.

General advocacy in the UN system

- Input into the work of the newly appointed Special Rapporteur on the right to health and of other rapporteurs with related mandates.
- Submit NGO “shadow” reports to expert committees responsible for reviewing country reports filed under a variety of treaties on discrimination and human rights.
- Make submissions to the Committee on Economic, Social

and Cultural Rights, and input into the work it is doing to prepare a General Comment on intellectual property.

- Work with government delegations at the UN Commission on Human Rights and similar bodies to promote resolutions solidifying in international law the right to access medicines.

Litigate using international mechanisms

- Where applicable, file communications with relevant UN bodies identifying breaches of the right to health in individual countries.
- Lodge petitions with the Inter-American Human Rights Commission alleging that denial of access to medication is in violation of instruments in that

regional system.

- File communications with the African Commission on Human and People’s Rights identifying the lack of government action to improve access to medications as a serious violation of the right to health set out in the African Charter of Human and People’s Rights.

Domestic lobbying, advocacy, human rights education

- Lobby governments for follow-up action on official pronouncements, such as the UN General Assembly’s Declaration of Commitment on HIV/AIDS and the resolutions of the UN Commission on Human Rights.
- Undertake a “human rights audit” of national legislation relevant to treatment access.

- Articulate an agenda for access to treatment and use it to engage government, legislators, the public, and the media.
- Organize workshops, public education forums, and skills-building sessions.
- Prepare media materials to promote informed coverage of the issue.

Domestic litigation

- Identify legal proceedings that would allow NGOs to advance human rights-based arguments for access to treatment. These could lend themselves to other, complementary advocacy activities and opportunities for media coverage.

Part II: Controlling Drug Prices

Controlling prices is another way to increase accessibility to treatments. Government intervention is a necessary and common feature of the pharmaceutical market in a majority of industrialized countries, *where more than three-quarters of drug expenditure is publicly financed in some way*.¹⁸ Yet the overwhelming majority of developing countries have no coordinated strategy to ensure equitable pricing. It is crucial that civil society advocate for the adoption of legislative provisions to regulate drug prices in developing countries.

Mechanisms Used in Industrialized Countries

Industrialized countries use demand-side and supply-side mechanisms to control prices. Demand-side mechanisms target the consumers of products, usually through public health insurance programs that reimburse or subsidize prices. Supply-side mechanisms target aspects of the supply of drugs, such as prices, profits, or costs.

Demand-side mechanisms can include:

- *Formularies.* These are lists of expenses that are eligible for reimbursement. The criteria for reimbursement may be based on particular drugs, or specific beneficiaries, or both. Some governments negotiate price reductions with manufacturers who want their drugs included on the formulary.
- *Co-payments.* Reimbursement schemes that are too generous may result in over-consumption or abuse. To avoid this situation,

consumers sometimes pay a fixed charge, known as a co-payment. However, co-payments discriminate against people who are less well off, particularly if they increase over time. As a result, tailored safety nets, such as exemptions for the poor and chronically sick, are often employed.

- *Hospital coverage.* Coverage of drugs in hospitals is usually subject to different rules because drug costs are included in hospital budgets. Due to their size, hospitals are usually able to negotiate individual price discounts with manufacturers.

Examples of supply-side mechanisms are:

- *Price fixing.* This involves assessing factors such as therapeutic value, comparison with existing products, and prices in other countries in order to establish “reasonable” prices. This process requires quite sophisticated methods.
- *Reference pricing.* This involves basing drug prices on the actual chemical contribution of a drug and any adjustments to its quality (or efficacy). This also requires complex evaluation methods.

Implications and Options for Developing Countries

The regulatory options exercised by industrialized countries are the product of intricate balances between domestic health-care priorities and industry interests. However, in order to ensure equity within such an environment, “public, private and non-profit decision-makers” must “agree on ways to segment the global market so that key technology products can be sold at low cost in developing countries without destroying markets – and industry incentives – in industrial countries.”¹⁹

Therefore, current initiatives to implement equitable pricing policies in developing countries should not include wholesale adoptions of legislative models from industrialized countries. Nonetheless, the legislative pricing frameworks adopted by developing countries will *also* be the outcome of balancing competing interests. Current internal and external pressures will influence precisely where this balance is struck. These pressures include:

- expectations that countries will contribute according to their abil-

- ity to pay in order to support drug innovation;
- industry warnings that incentives to develop innovative drugs for distinctly “South” diseases may be lacking if developing-country pricing policies do not ensure strong pharmaceutical profits; and
- domestic pressures (in some countries) to encourage an internationally competitive domestic pharmaceutical market.

Demand-side mechanisms are not likely to be effective in many developing countries because of limited financial resources. Therefore, supply-side mechanisms (ie, some form of price controls) are also needed.²⁰ Consideration should be given to employing a mix of the following strategies:

- *Differential pricing.* This involves manufacturers charging different prices in different countries based on local market conditions (a practice common in industrialized countries). Recently, many low-income countries have experienced a form of differential pricing as a result of voluntary price reductions by manufacturers. Mostly the result of price negotiations, some of these reductions have been successful, while others are more onerous because they come attached with stringent long-term conditions that reinforce patent protection.
- *The threat of compulsory licensing.* Brazil has successfully negotiated price reductions by threatening the use of compulsory licensing of pharmaceutical

products, which is permitted under Brazilian law in cases of “abusive pricing,” a national emergency, or failure to “work” a patent (ie, produce the product) in Brazil within three years of the patent having been granted.

- *Bulk buying.* A global procurement system for developing countries could use economies of scale to lower prices.
- *Generic competition.* Generic manufacturing can result in significant long-term reductions in pharmaceutical prices. For example, the governments of Brazil and Thailand, possessed of the domestic industrial capacity, have initiated local production of certain HIV/AIDS antiretrovirals. Where local production is not feasible, regional efforts may facilitate parallel importing of cheaper medicines.
- *Domestic price controls.* Price controls are a necessary component of any treatment accessibility policy.

Conclusion

Comprehensive drug pricing and financing strategies are used by most industrialized countries because they are necessary for the public interest. Inequities in drug accessibility between industrialized nations and developing countries is a global problem that can be addressed by advocating for equity pricing schemes in developing countries that are tailored to local social and economic conditions. Given the complexity of the issues, regional Cupertino is required to share technical expertise and experiences and to build momentum for access to treatment initiatives that cross borders.

Part III: The Role of Litigation

The Treatment Action Campaign (TAC) in South Africa is working to ensure that comprehensive treatment – including antiretroviral drugs – is provided to people living with HIV/AIDS, whether they have private medical insurance or whether they are among the majority of people in South Africa who have to rely on the public sector for their health care.

One of the tools that TAC uses to achieve this goal is litigation. South Africa has a long tradition of public interest litigation, dating back to the apartheid era. While the distinguishing feature of such litigation in the apartheid era was the attempt to control the exercise of public power and thereby reduce human rights violations, TAC's use of the law in securing access to treatment is to ensure – rather than prevent – state action. But while TAC recognizes that public interest litigation may be used as an important tool for social change, it also believes that the use of law should be limited and strategic, that the lawyer plays an important (albeit limited) role within a broader social movement, and that a comprehensive understanding of the political and economic context informs how the law is used to further the aims of the movement.

As a result, TAC's approach to the use of law is multifaceted. While TAC aims to secure a legal victory whenever litigation is undertaken, the organization is also highly aware of the role of the litigation process beyond the orders made in court judgments. Litigation places issues on the agenda, not only before a judge but also in the court of public opinion. In the much-publicized case involving the Pharmaceutical Manufacturers Association,²¹ one of TAC's primary objectives was to “turn a dry legal contest into a matter about human lives.”²² As well, by framing political

and moral demands in the language of legal rights and constitutional obliga-

Litigation places issues on the agenda, not only before a judge but also in the court of public opinion.

tions, TAC seeks to use the law without necessarily having to litigate.

Litigation Priorities

TAC has recently focused on three areas of litigation: the conclusion of the prevention of mother-to-child transmission of HIV (PMTCT) case; a complaint before the Competition Commission on excessive pricing of brand-name antiretroviral drugs and refusals to grant voluntary licences; and a constitutional challenge to the limited coverage for people with HIV/AIDS offered by the country's largest health-care insurer. Together, these cases target three obstacles to treatment – government, the brand-name pharmaceutical industry, and the health-care insurance industry.

PMTCT case. In December 2001, TAC succeeded in obtaining a court order that the government must (a) supply the antiretroviral drug nevirapine to HIV-positive pregnant women where public health facilities have the

capacity to do so and (b) plan and implement a phased rollout of a comprehensive national program to prevent MTCT. The decision was appealed but was upheld by South Africa's highest court. These decisions, and the public pressure mobilized by TAC and others, have led to movement by various provincial governments and even the national government. The main issue in this case was the extent to which a court may review policy decisions of the state. The outcome will have a significant ripple effect on both domestic and international efforts to legally enforce the right to health and other social and economic rights through court action.

The Competition Commission case. TAC is preparing an intervention in an existing complaint to the South African Competition Commission in which a generic company alleges that certain brand-name pharmaceutical companies have abused their dominance in the market by engaging in excessive pricing of their products, and by entering into exclusionary licensing or agency arrangements. TAC's objective is to ensure that South Africa's competition law is used to grant compulsory licences to ease the entry of generic antiretrovirals onto the market, thus bringing down prices. As it has in other cases, TAC will coordinate public campaigning to complement the legal process.

Insurance. TAC is contemplating legal action to challenge the limitation on benefits provided to people living with HIV/AIDS by one of the country's largest private health-care insurers. It will likely focus on cases in which treatment has been interrupted

during hospitalization because the private insurer's limits force the person to choose between having to pay the high costs of hospitalization out of pocket and relocating to a public health facility.

– Richard Elliott, Sharan Parmar,
Vivek Divan & Jonathan Berger

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¹ See Global Treatment Access: Legal Developments and Strategies. Canadian HIV/AIDS Legal Network. June 2002. Available on the website of the Legal Network (www.aidslaw.ca/barcelona2002/treatmentcomponent.htm).

² 14 UNTS 185. The Constitution of the WHO was adopted by the International Health Conference, New York, 19-22 June 1945; opened for signature on 22 July 1946 by the representatives of 61 states; and entered into force on 7 April 1948.

³ Charter of the United Nations, 26 June 1945 (entered into force 24 October 1945), TS 67 (1946).

⁴ *Ibid.*, Articles 55 and 56.

⁵ UDHR, Article 25(1).

⁶ *Ibid.*, Article 27(1).

⁷ ICESCR, Article 12.

⁸ ICCPR, Articles 6 and 9.

⁹ UN Committee on Economic, Social and Cultural Rights. General Comment 14: The right to the highest attainable standard of health (Art. 12). 4 July 2000. UN

Doc E/C.12/2000/4, CESCR at para 12. Available on the website of the United Nations High Commissioner for Human Rights via www.unhcr.ch.

¹⁰ *Ibid.* at paras. 33, 35, 36, and 37.

¹¹ Available on the website of the Joint United Nations Programme on HIV/AIDS via www.unaids.org.

¹² HIV/AIDS and Human Rights International Guidelines: Revised Guideline 6, available via www.unaids.org.

¹³ UN Commission on Human Rights, Resolutions 2001/33 (23 April 2001) and 2002/32 (22 April 2002). Available on the website of the United Nations High Commissioner for Human Rights via www.unhcr.ch.

¹⁴ Available on the website of the World Trade Organization via www.wto.org. For an overview of the TRIPS Agreement and its relation to the issue of access to medicines, see R Elliott, MH Bonin. Patents, International Trade Law and Access to Essential Medicines. Info sheet prepared for Canadian HIV/AIDS Legal Network & Médecins Sans Frontières Canada. May 2002. Available on the website of the Legal Network (www.aidslaw.ca/Maincontent/issues/cts/Patents-international-trade-law-and-access.pdf).

¹⁵ S Leckie. Violations of Economic, Social and Cultural Rights. *SIM Special No. 20*: 83.

¹⁶ See the full paper (supra, note 1) for specific examples of litigation brought before national courts and international or regional human rights bodies.

¹⁷ See E Carrasco. Derechos Humanos y el Acceso a Antirretrovirales en América Latina y el Caribe. *Acción Ciudadana Contra el SIDA (ACCS)*. Venezuela, January 2001, on file.

¹⁸ S Jacobzone. Pharmaceutical Policies in OECD Countries: Reconciling Social and Industrial Goals. Labour Market and Social Policy – Occasional Paper No. 40. Organization for Economic Development and Cooperation, 17 April 2000.

¹⁹ UNDP Human Development Report 2001: Making New Technologies Work for Human Development, 2001. United Nations Development Programme. Available on the UNDP website via www.undp.org.

²⁰ The Drug Price Control Order in India is an important example of a supply-side mechanism employed by a developing country that is beyond the reach of TRIPS. This mechanism is described in depth in the full paper (supra, note 1).

²¹ *Pharmaceutical Manufacturers' Association v President of the Republic of South Africa*, case no: 4183/98, High Court of South Africa (Transvaal Provincial Division) (March 2001), unreported case available on the website of the Treatment Action Campaign at www.tac.org.za/Documents/MedicineActCourtCase/affiavd.doc.

²² M Heywood. Debunking 'Conglomo-talk': A Case Study of the Amicus Curiae as an Instrument for Advocacy, Investigation and Mobilisation 12. Paper presented at Health, Law and Human Rights: Exploring the Connections – An International Cross-Disciplinary Conference Honoring Jonathan M. Mann, Philadelphia, PA, 29 Sept-1 Oct 2001. Available on the website of the AIDS Law Project via www.alp.org.za.

Introducing ARVs in Resource-Poor Settings: Challenges and Consequences

In most industrialized countries, AIDS mortality has plunged sharply with the advent of antiretroviral therapy. Yet the majority of people living with HIV/AIDS do not have access to modern HIV care, and some experts have argued that introducing such therapy is not a ranking priority. In this article, which is based on a plenary presentation at the XIV International AIDS Conference, Paul Farmer presents the experience of an integrated HIV prevention and care project in rural Haiti, and explores the challenges to national AIDS programs and other bodies in the “least developed” countries as more resources are made available for HIV prevention and care.

Introduction

AIDS-related debates are as old as the epidemic itself. The theme of the XI International AIDS Conference in Vancouver in 1996 was “One World, One Hope,” but delegates from some African nations predicted that the new combination antiretroviral (ARV) therapies would not be made available to the poor in Africa and in other settings with high burdens of both HIV and poverty. The people who were skeptical of our commitment to global health equity have been proven correct. Every year since 1996 should have brought us dozens of reports, from donor-supported HIV prevention and care efforts serving the poorest communities affected by HIV, about how best to deliver ARVs.

Instead, we have had years of debate in which HIV treatment and prevention are presented as discrete, indeed opposed, interventions. We have had studies of the variable impact of prevention efforts, quite divorced from HIV care. We have had a fair number of papers asking (and answering with confidence) the question, “Is it cost-effective to treat AIDS in poor countries?” These cost-effectiveness exercises, which usually con-

clude that it is not cost-effective to treat HIV disease in settings of great poverty, are based on scant data from the most affected continent, for three reasons. First, the costs of treatment and other “inputs” are rapidly moving targets. Second, the impact of effective therapy on transmission – or on prevention efforts – is poorly understood within settings of poverty. Third, relevant operational research has not been done because the projects do not exist. To do operational research, there must first be operations. “Africa cannot afford to wait two decades to tackle AIDS,” notes Ariel Pablos-Mendes. “Yet, the required research has been scant, owing to reservations about the feasibility of HAART [highly active antiretroviral therapy], clinical overconfidence and ethical paralysis.”¹

However, this “ethical paralysis” did not preclude transnational research projects that include First World diagnostics (viral loads, say) and Third World therapeutics. Acrimonious debate regarding the ethics of such research has, of course, also ensued.² As for treatment efforts,

we do have a few first-hand reports from across Africa, but these are not really donor-supported treatment projects. On the contrary, they are *patient-*

After almost a decade of experience with ARVs, what is our excuse for the lack of treatment programs in the poorest and most HIV-affected countries?

supported treatment efforts. In capital cities from Kampala to Cape Town, ARVs are readily available on the market, just as they are in every Latin American city surveyed by the Pan American Health Organization.³ These reports are often chilling, since (if they are candid) they include stories about (a) patients having to prove that they are able to pay for ARVs prior to enrolling in therapy; and (b) HIV-affected families in which one sick person is selected for treatment, while others in the same family are passed over.

What is our excuse for the lack of treatment programs in the poorest and most HIV-affected countries, after almost a decade of experience with ARVs? We can blame the high cost of pharmaceuticals, or shrug and point to the manifestly weak health infrastructures in such settings. But if we are honest, we will conclude that our own ambivalence regarding HIV therapy for the poorest has hamstrung

comprehensive efforts as much as anything else. It may be assumed that naturally conservative funders, looking for consensus and “safe bets,” would be unlikely to pay for such projects if they are so contested within the very community charged with promoting the health of the globe’s poor.

Obstacles to Delivering Treatment

Why this ambivalence among the public health community and humanitarian organizations? The impact of HAART in the United States, Europe, Australia, and Brazil has been profound, reducing mortality and even expenditures, often dramatically.⁴ Given strong proof of efficacy, and little consistent evidence of adverse impact on prevention in settings of poverty, why are we so reluctant to promote access for the poorest AIDS patients?

First, there is a deep rift in the international public health community regarding the treatment of those already sick with AIDS. Richard Feachem, recently named director of the Global Fund to Fight AIDS, Tuberculosis and Malaria, describes the rift in the following terms:

On one side is the opinion: “HAART is too difficult, too expensive, and too prone to divert resources from other priority health investments, fuel drug resistance, and undermine progress in behavioural change. We should not launch into this on a large scale.” On the other side is the position: “HAART is a human right. Therapy that is available to gay men in San Francisco and Sydney should also be available to all infected people everywhere. We have no choice and no alternative. We

must act on a huge scale and we must do so immediately.”⁵

Our leading medical journals are devoid of reports of treatment projects in Africa, but they do contain arguments pitting prevention against

There is much speculation, but little experience, linking prevention to care in the poorest communities.

treatment. “Data on the cost-effectiveness of HIV prevention in sub-Saharan Africa and on highly active antiretroviral therapy indicate that prevention is at least 28 times more cost-effective than HAART” reads the abstract of one recent review.⁶ Another self-proclaimed “systematic review of the evidence” concludes that the “most cost-effective interventions are for prevention of HIV/AIDS and treatment of tuberculosis, whereas HAART for adults, and home based care organized from health facilities, are the least cost effective.”⁷ Yet these conclusions were based not on real experience, but rather on a separate cost-effectiveness projection from South Africa and on a report of projected drug costs as applied to a project in urban Côte d’Ivoire.⁸

Second, no one seems to have actually done such projects in the world’s poorest communities, although HIV is now the leading cause of young-adult death in almost all of them. Thus, there is a lack of know-how regarding who should receive HAART, what the enrollment criteria would be, how to manage drug supply, and how best to monitor therapy in resource-poor settings.

There is much speculation, but little experience, linking prevention to care in the poorest communities. Cost-effectiveness analysis holds sway among policymakers even when it is not underpinned by experience or empiric research. Yet AIDS care, as Pablos-Mendes notes, “is learnt by doing it.”⁹

Our Experience in Haiti

Haiti is the Western hemisphere’s poorest and most HIV-affected nation. More than 15 years ago, Partners In Health and its Haitian sister organization, Zanmi Lasante, began a modest AIDS-prevention effort that was followed, much more recently, by a donor-supported treatment program. Our initial efforts, from the late 1980s until 1995, were focused largely on HIV prevention. Our group was the first to introduce voluntary counselling and testing into central Haiti, and the first to develop culturally appropriate prevention tools.¹⁰ Condoms were promoted and provided free of charge. Sexual education took place in schools, churches, and community meetings. The impact of these interventions, which reflected the consensus that prevention through education was the best we could offer, was limited by the growing poverty and political unrest that Haiti experienced during those years.¹¹ And even though our own efforts in rural Haiti were met with some measure of success – seroprevalence in our prenatal clinic has remained stable over the past several years – a growing number of young people returned from the cities sick with HIV acquired far from their home villages. By the early 1990s, over 25 percent of all admissions to our small hospital were HIV-related. By 1995, the proportion had grown to 40 percent.

By the mid-1990s, we had learned a number of key lessons, and we drew on them to design subsequent interventions. First, the results of local HIV-prevention efforts had no impact in faraway Port-au-Prince and other coastal cities, where the majority of transmissions were occurring. Second, the sick continued to return to their home villages, often to die. Third, fully half of these young people were sick with HIV-associated active tuberculosis, a proportion rivaled only in certain slums in Haiti's largest city.¹² Fourth, this substantial subset of patients would not die in the short term if they were to receive effective TB treatment. So in addition to continuing our prevention efforts, we redoubled our efforts to detect and treat every case of active TB in patients diagnosed with HIV infection. From the outset, then, our HIV and TB activities were linked.

In 1995-96 we introduced AZT into our prenatal clinic formulary. As a result, the number of women seeking testing during pregnancy rose sharply (from 15-20 percent two years earlier to over 90 percent). Most women, of course, were found to be seronegative, which afforded important opportunities for prevention. Among women found to be infected with HIV, mother-to-child transmission became rare. More recently, nevirapine further improved the impact of this effort, since it could be given even in tardily diagnosed HIV infection among parturient women.

In 1998, we launched the HIV Equity Initiative to complement prevention efforts. We provided ARV therapy to people for whom prevention had failed and who would, in our opinion, soon die without these drugs. The care component included an uninterrupted supply of ARV

agents, but only modest lab infrastructure; CD4 counts and viral loads were not available in Haiti. Use of ARVs has been supervised by com-

The transformation of AIDS from an inevitably fatal disease to a chronic and manageable one has decreased stigma dramatically in Haiti.

munity-based health workers who are called *accompagnateurs* and who visit patients each day and ascertain that the pills are ingested. By the spring of 2002, between 10 and 12 percent of the over 2000 HIV-positive patients followed in our clinic were receiving such therapy. In contrast to the scenario described above, in which African patients were granted access to ARVs if they could prove that they could pay for them, rural Haitian patients are selected exclusively on the basis of clinical status. A clinical algorithm, described elsewhere, is used to help identify those patients in greatest need.¹³

According to clinical and virological criteria, the HIV Equity Initiative has been effective. We have also found that by improving clinical services for people living with HIV/AIDS, we can improve the quality of prevention efforts, boost medical staff morale, and reduce AIDS-related stigma. The transformation of AIDS from an inevitably fatal disease to a chronic and manageable one has decreased stigma dramatically in Haiti. To cite the experience of one patient: "I was a walking skeleton before I began ther-

apy. I was afraid to go out of my house and no one would buy things from my shop. But now I am fine again.... My wife has returned to me and now my children are not ashamed to be seen with me. I can work again."

Often enough, people seeking to assess a particular intervention will see just what they want to see. It is easy to predict that people who argue against making ARVs available to the poorest will soon point to the problems: acquired resistance to these drugs, thievery and sale on the black market, adverse drug effects, diversion of resources from higher-priority projects, and so on. But one positive effect of integrating treatment should not be ignored: for over a decade, those living with both poverty and HIV (they are tens of millions strong) have been demanding access to effective therapy. Thus, merely introducing donor-supported HIV treatment efforts is positive because it shows we are listening, at long last, to these voices.

Conclusion

With the exception of \$100,000 in start-up funds from a foundation based in Haiti, the HIV Equity Initiative has never received support from a major foundation or international body charged with responding to AIDS. This will all change in the coming year if Haiti is awarded funds from the Global Fund to Fight AIDS, Tuberculosis and Malaria. As we, and other groups based in regions in which poverty and HIV are the ranking threats to health, contemplate the advent of new resources, we need to ask hard questions of ourselves and also of those who will evaluate the use of these funds. In seeking to promote accountability, will we develop yet

another set of burdensome reporting requirements that will force us to hire expensive consultants from far beyond the boundaries of afflicted communities? Or will we seek innovative and realistic means of evaluating the impact of long-overdue investments?

Within every community beset by poverty and HIV are scores of willing individuals who wish to be trained to serve as community-health workers. Working with these *accompagneurs*, we can develop lower-cost means of assessing impact so that resources may be channeled into food, water, and improved housing for HIV-affected families. Such resources are better spent on salaries for health workers than on yet another round of per diems and consulting fees for “experts.” Such resources can also be spent on improving TB diagnosis and treatment, and on linking HIV services to prenatal care. Indeed, we can use this moment to atone for our collective inattention to a host of preventable or remediable afflictions.

If we succeed, we may at the same time develop truly novel strategies for assessing the impact not of our largesse, but rather of our long-overdue attempts to remediate the

obscene disparities of risk and access that characterize the global AIDS pandemic.

– Paul Farmer

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"I Have No Watch, But I Haven't Missed a Dose"

Anyone who was fortunate enough to hear Fred Minandi speak in Barcelona must have been moved by what he had to say. Mr Minandi is a person living with HIV/AIDS from Chiradzulu, Malawi, who spoke at *Time to Treat: Transforming AIDS Treatment from Right to Reality*, a satellite meeting of the XIV International Conference on AIDS held on 7 July 2002, and sponsored by Médecins Sans Frontières (MSF) and the Health Global Access Project. His presentation is a passionate, first-hand account of how antiretroviral therapy has transformed lives, how it has given hope to people, how it has helped to reduce the stigma against AIDS in his community, and how it has contributed to prevention efforts.

I am one of the patients who is benefiting from antiretroviral (ARV) therapy in a project run by MSF. My name is Fred Minandi. I am 42 years old and I am a farmer in Malawi. I have a wife who is also a farmer, and two children. The eldest one is married, while the other one is still at school. My village is in a rural district and I have a grass-thatched house with one bedroom. I am earning money from my garden where I grow crops for food.

Malawi is probably one of the poorest countries in Africa and is one of the countries with the highest incidence of HIV in Africa. Fifteen percent of the adult population is infected with HIV. Where I am living, 24 percent of the pregnant women who have been tested are HIV-positive. Ten percent of the youth from the secondary school are also infected. These figures have been given to me, but what I see in my village is young people too sick to be able to cultivate their gardens and to feed their families. Families are spending a lot of money trying to find drugs, which could help the sick ones, without result. I have seen parents dying, leaving orphans to be

cared for by the elderly, who have no means and no hope of giving them a future.

I started to be sick in 1997. I have been sick on and off for the last four years, to the point that it was difficult for me to work or even to do anything. I was tested in 2001. I was lucky to live in a place where MSF had just started ARV treatment. I am one of the first patients to get ARVs for free in Malawi. If I am able to be here today to speak with you, it is

Today, my life is attached to these drugs and I don't think that I can forget to take them.

because of this treatment. There are some people who say that in Africa people will not be able to take drugs because they cannot tell time. I can assure you that although I have no watch since I started taking my triple therapy in August last year, I haven't missed one dose.

Why? Because Margot, the MSF nurse, took a bit of time to explain to

me how these drugs were working. She told me that if I was not serious enough to take them very regularly, the drugs could not work any more. She explained what the side effects would be, and that it would be better after a while. It was tough. I got nauseous at first, but after two months the nausea disappeared. Now, these drugs are much easier to take. Today, my life is attached to these drugs and I don't think that I can forget to take them.

All of my friends who are in the support group for people living with AIDS feel the same way. We are 60 in this group, and we meet regularly every month to be able to speak together. We explain to the ones who get treatment what to do if they have side effects. We explain to them that the side effects will stop. We help each other if someone is too sick to come to collect his or her drugs. For some in our group who have nobody to tell about their HIV and their treatment, we become guardians. This means that we go with them to the compliance session, and that we help them to take the drugs at home. We try to support the family if one of us dies, but mainly we speak about how the treatment gave us our life back, and about the improvements we notice almost each and every day. We try now to have some small income-generating activities to be able to support some of us who are poor. We inform our community about all the medical services that are available for everybody in the district (the HIV clinic, the program for the pregnant women infected, the voluntary counselling centre, where to get condoms, where to get information).

My CD4 count was 107 when I started the treatment. Today, it has risen to 356. I am very proud of that.

When I was sick, I knew I had HIV, but I would never admit it or speak about it. Speaking about it would have not changed anything for me

My neighbours are talking to me again. Treatment is the best tool against stigma.

except making me depressed. My neighbours were seeing me becoming weaker and weaker every day. Of course, they all knew what I had, but nobody asked me about it. They just gradually stopped coming to see me. Most of the people in Malawi are like that. They don't speak because they don't want to know. It is why my country is dying in silence.

Today, I am back in my field, back in my church. I can feed my family. In the last couple of years, I was able to harvest only about two bags of maize because I was too weak. Now, I am planning to harvest 10 bags of maize just this year alone. I feel have a future. My neighbours started coming to see me again like before. I, myself, feel that I have changed. I can now talk to my children, telling them that I have AIDS. I tell my neighbours, too. When there is a meeting in the district, I go and speak about my disease because I am not ashamed anymore. I know that I will not be rejected because now I am just like everybody else. Somebody with AIDS who is very sick makes everybody afraid because you see your own death in his or her eyes. But when you are under treatment,

you feel and look better, and then people do not reject you. I would like to say to all the people at this conference that treatment is the best tool against stigma. I used to think that there was no hope for those of us living with HIV, but treatment has changed this.

There are some other people who also said that treatment is too expensive and therefore only prevention should be done in a country like Malawi. First of all, would that mean that I would have to die with all my friends in the PWA group, as well as with the one million people who are already infected in Malawi? For us, talking about prevention is too late, but I believe we still have the right to be treated. I would like to say that I consider my life important, not only for me but for my family and my country as a whole. I feel that whatever little I contribute for my family, friends, relatives, neighbours, and to the Malawi nation, this complements the work of all those who are feeding Malawi.

Secondly, I think that having affordable treatment available will encourage people to know about their serostatus more than when there is nothing to be offered. It will help break the silence. My friends and I from the PWA group have been trained as counsellors. We are convincing a lot of people to go for testing because they know that if they are already positive, they will be treated. They know they will have a real benefit for themselves. They see what the treatment has done for us.

Thirdly, we are using generic medicines from India in the program in Malawi, which keeps the price as low as possible. The less expensive

the drugs, the less expensive the program, and the more people can be treated. I would like to say that prevention and treatment are linked together. I am sure that, today, I can convince more people to change their behaviour, to use a condom, to go for testing. Why? Because I am treated myself. I can also tell them that treatment is still difficult and that they have to try hard to stay negative. I would also like to ask those people who say we should only do prevention: If this epidemic were claiming so many lives in your community, would you really accept letting all of us already living with HIV die? I hope I will be able to meet a lot of people who are also HIV-positive and who could help me become more active. We are the ones who need these drugs and we are the ones who need to fight for it. I hope that our voice will convince the people who are being asked to give money for drugs to do so and not to give only for prevention.

In closing, I would like to appeal to all the pharmaceutical companies manufacturing ARVs to reduce the prices of their drugs for all low-income countries; to our national governments to support treatment and ask for help; and to rich governments to give us the money to be able to do it. The war against HIV/AIDS can only be won if we all come together. Thank you for your attention. It was my first time for me to go out of Malawi, and it is incredible.

— Fred Minandi

Fred Minandi can be contacted via the Campaign for Access to Essential Medicines, Médecins Sans Frontières at access@geneva.msf.org.

Advancing Research and Access to HIV Vaccines: A Framework for Action

In light of the continuing spread of HIV infection and the devastating impact of the disease on lives, communities, and economies, particularly in the developing world, the investment in new treatments, vaccines, and microbicides has clearly been inadequate. Efforts must be intensified to develop effective HIV vaccines and to ensure that they are accessible to people in all parts of the world. This article is a summary of a paper by Sam Avrett¹ presented at “Putting Third First: Vaccines, Access to Treatments and the Law,” a satellite meeting held at Barcelona on 5 July 2002 and organized by the Canadian HIV/AIDS Legal Network, the AIDS Law Project, South Africa, and the Lawyers Collective HIV/AIDS Unit, India. In the article, Avrett calls for immediate action to increase commitment and funding for HIV vaccines, enhance public support and involvement, accelerate vaccine development, and plan for the eventual delivery of the vaccines. The article briefly outlines steps that governments need to take to implement each of these objectives. The article also provides a menu of potential actions for vaccine advocates to consider as they lobby governments.

Introduction

The global AIDS crisis is still beginning. HIV is the fastest spreading lethal infectious disease in the world today, and is in itself a major global health catastrophe.² In resource-limited countries, HIV and AIDS have unfortunately taken their place beside other major public health needs related to infectious disease (such as tuberculosis and malaria); basic environmental health challenges (such as clean air and water); challenges of basic nutrition, shelter, and education; unresolved political conflict; and egregious social and economic inequities. The current human and economic costs of HIV and AIDS will be vastly outweighed by the costs of the coming epidemic, especially if the world takes insufficient action. By any standard, the current effort against AIDS, including research on new treatments, vaccines,

and microbicides, is not yet sufficient.

The powerful, historical impact of other vaccines in halting disease supports the case for HIV vaccine development. In addition, given the relative cost and potential benefit of HIV vaccine development, the HIV vaccine effort should be seen as one of ethical benefit and justice. 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 responses to the epidemic. As with low-cost HIV treatments, diagnostics, and potentially effective vaginal microbicides, it would be unethical not to invest in development of HIV vaccines and in efforts to make them accessible.

The scientific case for moving forward is clear. The feasibility of

developing effective HIV vaccines is rooted in scientific data: several experimental HIV vaccines have been shown to protect monkeys against HIV infection and to generate immune responses in people. The evidence of the potential feasibility of HIV vaccine development is equal to, or greater than, the immunologic and empirical evidence that existed for the feasibility of vaccines against Lyme disease, rotavirus, and pertussis (whooping cough) before those vaccines entered into large-scale clinical trials. Furthermore, the scientific potential for an HIV vaccine may be

By any standard, the current effort against AIDS, including research on new treatments, vaccines, and microbicides, is not yet sufficient.

increasing more rapidly than the pace of global vaccine development funding, thus widening the gap of relative underinvestment. In short, investment in HIV vaccine development efforts must accelerate not only because HIV vaccines are needed, but also because HIV vaccines are becoming increasingly possible.

If effective HIV vaccines are to become available and accessible, immediate action is required to:

- increase commitment and funding;
- enhance public involvement and support;
- accelerate vaccine development; and
- promote accessibility.

Increase Commitment and Funding

Successful vaccine development and access will require a coordinated and concerted global effort. Commitments are needed at all levels – local, national, and international – and from all sectors, including government, the private sector, and civil society. Commitments by national governments are particularly important to the global HIV vaccine effort. These commitments would best be expressed through the development of national HIV vaccine plans. National plans are especially needed in all of the countries now engaged in HIV vaccine development. National plans should be milestone-driven and should cover strategies and timelines for pre-clinical and clinical research; development and manufacture; regulatory review and approval (of both clinical research and new vaccines); field safety and effectiveness research; and vaccine delivery.

Funding is also essential for HIV vaccine development. Analyses of overall global investment in HIV vaccine development by several leading HIV vaccine policy groups place the world's effort in 2000 for HIV vaccines at approximately US\$470 million per year.^{3,4} This number may have doubled by 2003. But even with recent increases, the amount represents a small investment relative to total world spending on health, education, and research. In the late 1990s, the world's combined gross national product (GNP) was valued at approximately US\$30 trillion. Approximately US\$1750 billion of this was spent on health each year, another US\$1750 billion on education, and US\$71 billion on health research and development.^{5,6} Specific, increased funding targets

are needed for all governments, but particularly for governments of high-income countries.

Specific, increased funding targets are needed for all governments, but particularly for governments of high-income countries.

When lobbying for increased commitment and funding, vaccine advocates should consider the following potential actions.

1. Define and compare models for national HIV vaccine plans. This would involve research and analysis of:
 - experiences in initiating national planning;
 - processes and resources for developing and finalizing national plans;
 - models for participation and transparency in national plan development;
 - specific components and the language of national plans;
 - the degree of enforceability of, and accountability for, tasks, timelines, and lines of responsibility; and
 - anecdotal and quantitative evidence of the positive impact of plans.
2. Define and compare models for national funding of HIV vaccine development. This would involve research and analysis of:
 - current and ideal levels of HIV vaccine-related funding at large national research agencies;
 - current and ideal levels of funding from national governments to HIV vaccine-related programs at multilateral agencies;
 - current and ideal levels of funding from national governments to public-private partnerships (such as the International AIDS Vaccine Initiative); and
 - current and ideal levels of direct bilateral funding from national governments in high-income countries to governments of low-income and middle-income countries to support HIV vaccine clinical trial infrastructure; technology transfer for HIV vaccine research, development, and manufacture; regulatory and ethical review capacity; and public health infrastructure for vaccine delivery.
3. Work at a national level to propose and expand national plans and funding commitments. This would involve meeting with policy- and decision-makers to propose models, options, and targets; and building national coalitions to support expanded national plans and funding commitments.

Enhance Public Involvement

The HIV vaccine effort now involves more than 25 national governments and dozens of communities, private-sector companies, research institutions, and other local, national, and international agencies. Once developed, HIV vaccines will potentially be licensed and used in every part of the world. Energy and expertise from many sectors are needed to ensure that HIV vaccine development and access is supported, coordinated, and locally relevant. A wide range of input and perspectives is also needed to ensure that the development and

use of HIV vaccines is consistent with broad public health and human rights goals.

The definition of “public” input and involvement must include individuals who claim a wide range of affiliations, including public- and private-sector researchers, leaders of pharmaceutical and biotechnology companies, national government leaders, research trial participants, people living with HIV, local political leaders, religious leaders, business and labour union leaders, journalists, legal advocates, youth advocates, civil rights advocates, community educators, and local philanthropists and foundations.

The goals for public involvement in HIV vaccine development⁷ should be:

- increased **public understanding** about basic concepts of HIV, public health, HIV prevention, vaccines, biomedical research, and human rights;
- increased **public support** for HIV vaccine research, development, and access, particularly through coalitions and partnerships that allow participation, information exchange, and ongoing communication, training, and support; and
- increased **public participation** as measured by the inclusivity, diversity, and dynamism of multi-sectoral involvement in HIV vaccine-development collaborations and partnerships.

Public support for HIV vaccine development will depend on the creation of coalitions, partnerships, networks, and alliances that facilitate stakeholder participation, information exchange, and ongoing communication, training, and support.

In seeking to increase public

involvement, vaccine advocates should consider the following potential actions:

Energy and expertise from many sectors are needed to ensure that HIV vaccine development and access is supported, coordinated, and locally relevant.

1. Define and compare models for public understanding, support, and participation. This would involve research and analysis to identify:
 - best-practice programs, strategies, and tools to increase public understanding about HIV vaccine development. These could include models for educational methods, materials, and networks to support dialogue and learning about the basic concepts of HIV, public health, HIV prevention, vaccines, biomedical research, and human rights;
 - best-practice strategies to build public support for HIV vaccine research, development and access. These could include models of transparent and accessible networks; and models of coalitions that cross geographic, professional and institutional affiliations, and that cross gradients of social and economic power; and
 - current models to ensure public participation in HIV vaccine research and development, such as bylaws and guidelines governing membership and participation in clinical trial planning committees, vaccine development part-
2. Build public understanding by working at a local, national, and international level to:
 - develop and disseminate user-appropriate materials about basic concepts of HIV, public health, HIV prevention, vaccines, biomedical research, and human rights;
 - train, fund, and partner with experienced opinion leaders (such as political leaders, journalists, community advocates, research trial participants, researchers, government officials, and company representatives) to improve their understanding of current HIV vaccine issues, and to support their efforts in communicating accurate information and in mobilizing public interest;
 - support the capacity of potential and new opinion leaders to disseminate information and education about HIV-vaccine development and broader issues of public health; and
 - integrate basic HIV-vaccine information into general AIDS and public health messages.
3. Build public support by advocating with governments, industry, community organizations, and other institutions to create and expand networks at a local, national, and international level that are able to:
 - provide information about HIV-vaccine development history, funding, and products, as well as research, development, and access efforts;
 - provide information about aspects of clinical trial design, including research recruitment

and retention, informed-consent protocols, risk-reduction protocols, and strategies to prevent social harms;

- support integration of clinical trial planning, recruitment and education into ongoing community-based care settings, public health education efforts, and HIV-prevention efforts;
 - support information and dialogue about experimental vaccine products, proposed trial designs, and decision-making processes for efficacy testing, licensure, and deployment of vaccines;
 - support strategies for community organizing, national lobbying and advocacy, and communications.
4. Build public participation by working at a local, national, and international level to improve bylaws and guidelines governing membership and participation in clinical trial planning committees, vaccine-development partnerships, and ethical and regulatory review committees; and to create adequate incentives and support for initial and sustained participation.

Accelerate Vaccine Development

Private-sector for-profit companies are indispensable to ensure the development of HIV vaccines and other technologies for improved health in the world's poorest countries, particularly because they have the mission, structure, and potential resources to bring new products to market as quickly and efficiently as possible. However, in HIV vaccine development, the private, for-profit sector is dissuaded by a combination of economic disincentives and opportunity costs, collectively (and dismally) called "market failure." Few pharmaceutical companies are willing to risk

hundreds of millions of dollars of investment in HIV vaccine research. In fact, given low profit margins,

A laissez-faire approach to private-sector research and development will not result in the development of HIV vaccines for use in the developing world in a reasonable time frame.

high-volume production requirements, and liability concerns related to vaccines, only a few large companies engage in any vaccine development and manufacturing. Hence, a laissez-faire approach to private-sector research and development will not result in the development of HIV vaccines suitable and accessible for use in the developing world in a reasonable time frame.⁸ Therefore, governments need to take steps to:

- directly fund private-sector HIV vaccine development;
- enact research tax credits for private-sector HIV vaccine development;
- support public-private partnerships focused on HIV vaccine development; and
- increase funding of research, development, and delivery infrastructures.

In their efforts to persuade governments to invest more in vaccine development, advocates should consider the following potential actions.

1. Define and compare models and current efforts for accelerating research and development of HIV

vaccines and other new public health technologies. This would require research and analysis to identify:

- the current plans, funding sources, contract mechanisms, amounts, destinations, and deliverables of direct government funding for both (a) private-sector vaccine development; and (b) public-sector research, development, and delivery infrastructures;
- the proposed language, current status, and prospects of research tax credits and other legislative incentives for private-sector HIV vaccine development; and
- the current models for public-private partnerships in HIV vaccine development, and the successes and challenges experienced by those partnerships.

2. Work at a national level to propose and expand best-practice models. This would involve meeting with policy- and decision-makers to propose new initiatives and targets. It would also involve building networks to support the creation and expansion of direct government funding of private-sector HIV vaccine development; research tax credits for private-sector HIV vaccine development; public-private partnerships focused on HIV vaccine development; and government funding of research, development, and delivery infrastructures.

Promote Accessibility

Widely accessible HIV vaccines would likely have the highest comparative benefits in countries and communities with the least resources and the highest HIV infection rates.

The fundamental human obligation to share in scientific advancement and its benefits is embodied in several international rights documents, including the 1975 Charter of Economic Rights and Duties of States:

All States should facilitate the access of developing countries to the achievements of modern science and technology, the transfer of technology, and the creation of indigenous technology for the benefit of the developing countries in forms and in accordance with procedures which are suited to their economies and needs.⁹

Access to vaccines has long been a global challenge. Although there have been some successes (eg, polio), international health agencies have struggled to achieve high rates of vaccination against most diseases. Access to an HIV vaccine will also be a challenge. Therefore, governments need to take steps now to:

- address intellectual property rights, international trade law, and regulatory systems to increase access to new health technologies, while maintaining adequate health and human rights protections and incentives for private-sector invention and product development;
- increase global demand for vaccines;
- expand sales tax credits, liability compensation systems, and support for differential pricing for future HIV vaccines; and
- improve infrastructure for vaccine delivery.

Vaccine advocates working on access issues should consider the following potential actions.

1. Document and compare models and current efforts to ensure that

developing countries fully share in the scientific achievement and benefits of new HIV vaccines. This will involve researching and analyzing:

- the international environment for HIV vaccine-related inventions and ownership, including current HIV vaccine-related patents;
 - the environment and contractual arrangements for vaccine licensure, trade, and technology transfer, including arrangements within current vaccine development efforts to ensure sublicensing and local manufacture to provide access to potential HIV vaccines;
 - standards and models for international and national vaccine procurement, distribution, delivery, and access;
 - current literature and estimates of potential demand for HIV vaccines;
 - the proposed language, current status, and prospects of vaccine-related sales-tax-credit legislation, liability compensation legislation, and legislative initiatives to demonstrate support for global differential pricing; and
 - successful models for delivery of new vaccines.
2. Work at a national and international level to propose and expand best-practice models. This will involve building networks and meeting with policy- and decision-makers to propose new initiatives and targets.

Conclusion

It is clear that governments and other stakeholders must move forward on several fronts if an effective and accessible HIV vaccine is to become a reality. Vaccine advocates will want

to review the actions proposed in this paper as they work to develop advocacy strategies. Whatever strategies are adopted, vaccine advocates will need to work at a national level to monitor and hold governments and other stakeholders accountable. This will involve regularly documenting progress toward milestones and funding targets, and proposing remedies and action through meetings, reports, and other advocacy.

— Sam Avrett

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¹ See S Avrett. HIV Vaccines for Developing Countries: Advancing Research and Access – Summary. Canadian HIV/AIDS Legal Network. May 2002. Available on the website of the Legal Network (www.aidslaw.ca/barcelona2002/hivvaccinecomponent.htm). For a related article, see also S Avrett, C Collins. HIV vaccines: current challenges and future directions. *Canadian HIV/AIDS Policy & Law Review*. 2002; 7(1): 1, 20-25. Available on the website of the Legal Network (www.aidslaw.ca/Maincontent/otherdocs/Newsletter/vol7no12002/vaccines_challenges.htm).

² UNAIDS. AIDS Epidemic Update. December 2001. Available on the website of UNAIDS via www.unaids.org.

³ International AIDS Vaccine Initiative. Accelerating the Development of an AIDS Vaccine for the World. July 2001. Available on the website of IAVI via www.iavi.org.

⁴ S Avrett, D Cappelletto, C Collins et al. Six Years and Counting: Can a Shifting Landscape Accelerate an AIDS Vaccine? AIDS Vaccine Advocacy Coalition. Washington, DC: 2001. Available on the website of AVAC via www.avac.org.

⁵ World Bank. World Development Report 2000/2001. Washington DC: 2001, Tables 6-7.

⁶ V Neufeld, S MacLeod, P Tugwell, D Zakus, C Zarowsky. The rich-poor gap in global health research: challenges for Canada. *Canadian Medical Association Journal*. 27 April 2001, 164 (8): 1158-1159.

⁷ These three goals were defined by a working group at the international expert consultation held by the Canadian HIV/AIDS Legal Network in Montréal in April 2002.

⁸ M Ainsworth et al. Accelerating an AIDS vaccine for developing countries: Recommendations for the World Bank. World Bank AIDS Vaccine Task Force. 2000. Available on the website of the International Academy of Chiropractic Neurology via www.iaacn.org.

⁹ UN General Assembly. Charter of Economic Rights and Duties of States, 1975. Chapter II, Article 13.

Juggling Individual and Collective Concerns with Respect to HIV/AIDS Policies

Efforts to prevent the spread of HIV infection sometimes give rise to tensions between individual and collective rights. This article, based on a presentation by Nelson Varas-Díaz (abstract TuOrG1171), explores these tensions in the context of the laws and policies of eight Latin American countries: Costa Rica,¹ Dominican Republic,² Ecuador,³ Guatemala,⁴ Honduras,⁵ Nicaragua,⁶ Panama,⁷ and Puerto Rico.⁸ The article describes five elements of the response to HIV/AIDS in which tensions between individual and collective rights have surfaced: the participation of people living with HIV/AIDS on national commissions; the ability of HIV-positive persons to access antiretroviral medications; HIV-antibody testing practices; the confidentiality of health information; and the rights and duties of people living with HIV/AIDS. The article concludes that the success of programs designed to prevent the spread of HIV infection depends on the ability of societies and governments to balance the tensions between individual and collective rights.

Introduction

When a state introduces policies to prevent the spread of HIV/AIDS among its population, it regulates the nature of social relations. The state establishes the manner in which social relations that could lead to new infections should be carried out, and how it will relate to those already infected. The state has an interest in regulating social relations in order to prevent new infections and to protect public health. In the process, the state distinguishes between “sick people” and “healthy people.” Such distinctions can cause more problems than provide solutions. For example, they may cause people to think the epidemic is solely of concern to those already infected. They can also foster prevention efforts that concentrate on the infected and not on society in general. Finally, they can lead to the development of tensions between individual and collective perspectives.

HIV transmission is intimately related to acts that people consider

private (eg, unprotected sex and needle sharing). Nevertheless, the state views these individual actions as having collective repercussions if they lead to HIV infection. This is the beginning of a tug-of-war in which guarding collective health and well-being is on one side and individual rights are on the other. Our research revealed five dimensions in which the tensions between individual and collective perspectives were manifested. Each dimension is described below.

The Participation of People Living with HIV/AIDS on National Commissions

The development of commissions to address the HIV pandemic has been common throughout the world. They are usually composed of representatives from a wide variety of sectors of society, including government agencies, the private sector, religious groups, non-governmental organiza-

tions, and people living with HIV/AIDS. The laws or policies of all of the countries in this study, except Panama, stipulate the creation of such structures. Nevertheless, the participation of HIV-positive people in these commissions is limited. In some countries, they occupy only two of the 12 positions on a given commission. On many commissions, the role of the HIV-positive members is unclear. The failure to adequately involve people living with HIV/AIDS in these national commissions underscores the tensions between individual and collective perspectives.

Access to Medical Services and Antiretroviral Treatment

Despite their limitations, antiretroviral drugs are an effective strategy for dealing with the consequences of HIV/AIDS. For certain populations, access to antiretroviral drugs has been limited because of their cost and for other reasons. Access to treatment is mentioned in the laws and policies of all the countries in this study, except Honduras. However, the definition of treatment is vague. Only the laws and policies of Costa Rica, Guatemala, and Puerto Rico specifically mention access to antiretroviral treatment. The message seems clear: although HIV/AIDS impacts everybody, treatment of those already affected is not a priority.

Voluntary Nature of HIV-Antibody Testing

The laws and policies of all countries in this study, except Ecuador, state that HIV testing is a voluntary practice. Nevertheless, they also outline instances in which mandatory testing

can be carried out. These instances include divorce procedures, those in the sex industry, participants in high-contact sports, those under criminal investigation, suspicion on the part of a spouse that their partner is positive, requests from physicians, and in cases where government feels the need to intervene with particular populations. It is clear that in such instances, the voluntary nature of testing is undermined by the perceived needs of public health. The collective right to health prevails over individual rights to voluntary testing.

Confidentiality in Case Reporting

The laws and policies of all the countries in this study state that cases of HIV infection will be reported to health authorities on a confidential basis. Nevertheless, there are concerns about how this is to be done. Only Costa Rica, Nicaragua, and Puerto Rico mention the use of numerical coding to ensure confidentiality. The laws of Dominican Republic, Ecuador, Honduras, Guatemala, and Panama do not specify how this process will be carried out. These unclear procedures can lead to overt discrimination against people living with HIV/AIDS and can create the impression that being tested is a potentially dangerous activity.

Rights and Duties of People Living with HIV/AIDS

The laws and policies of all the countries involved in this study include special sections that spell out both the rights and the duties of HIV-positive people. These rights include the right not to be discriminated

against, the right to have access to educational institutions, to reveal

Laws and policies impose on HIV-positive people duties that are rarely imposed on others.

one's serostatus to an employer, to have a public life, and to have access to employment. (The right not to be discriminated against is mentioned in all the countries except Honduras.) The duties include informing one's sexual contact of one's serostatus, practising responsible sexuality, and revealing one's serostatus to health professionals.

The fact that people living with HIV/AIDS need to be protected against discrimination from others in society highlights the tension between individual and collective perspectives. This tension is even more evident when one considers that laws and policies impose on HIV-positive persons duties that are rarely imposed on others. Some of these duties infringe on the rights of people living with AIDS in the name of public safety. Thus, the collective's right to health is prioritized over the rights of HIV-positive people. This is also evident in the fact that some laws penalize the intentional transmission of HIV and include powers to restrain people who engage in dangerous conduct.

Conclusion

Effective prevention of the spread of HIV depends on how society addresses the tensions between individual and collective rights and con-

cerns. It is the responsibility of the state to address these issues when developing AIDS-related policies. States could be confronted with an enormous pandemic if they do not effectively curb the spread of HIV. At the same time, states could be confronted with an underground or hidden epidemic if they insist on establishing policies that do not address the issue of human rights for people living with HIV/AIDS. States, and the communities affected by the epidemic, must find a way to balance these tensions.

— presented by Nelson Varas-Díaz

The research covered in this article was conducted by Nelson Varas-Díaz and José Toro-Alfonso. For an extended description of the research, contact the authors at: University Center for Psychological Services and Research, University of Puerto Rico, PO Box 23174, San Juan, PR 00931-3174 (email: nvaras@rrpac.upr.clu.edu).

¹ Law 7771 (1998). *Ley general sobre el VIH/SIDA. Leyes y Reglamentos sobre SIDA Vigentes en Centroamérica*. Guatemala: Proyecto Acción SIDA de Centroamérica.

² Law 55-93 (1993). *Ley 55-93 sobre el SIDA*. Santo Domingo, República Dominicana: Impresora Gonzalito.

³ Registro Oficial (2000). *Ley para la Prevención y la Asistencia Integral del VIH/SIDA*. Organismo del Gobierno de Ecuador: Quito, Ecuador.

⁴ Decreto 27-2000-06-26 (2000). *Ley general para el combate del Virus de Inmunodeficiencia Humana y el Síndrome de Inmunodeficiencia Adquirida y de la promoción y defensa de los derechos humanos ante el VIH/SIDA*. Supra, note 1.

⁵ La Gaceta (13 November 1999). Poder Legislativo: Decreto No.147-99, 1-7.

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⁷ Law 3 (2000). *Ley general sobre las infecciones de transmisión sexual, el Virus de Inmunodeficiencia Adquirida y el SIDA*. Supra, note 1.

⁸ Varas-Díaz N, Toro-Alfonso J. A review of HIV/AIDS-related policies in Puerto Rico: Implications for psychology. *Caribbean Studies*. University of Puerto Rico (forthcoming).

Toward a More Meaningful Involvement of People Living with HIV/AIDS

All too often, the involvement of people living with HIV/AIDS in AIDS NGOs is tokenistic rather than meaningful. This article, which is based on a presentation by Christophe Cornu (abstract WeOrGI292), demonstrates that, under the right conditions, the involvement of people living with HIV/AIDS can be beneficial both for the individuals and for the NGOs. The article describes the beneficial impacts of involvement observed in a study conducted in Burkina Faso, Ecuador, India, and Zambia. It also discusses the harmful effects of involvement, for individuals as well as NGOs, identified by study participants. The article concludes with a series of recommendations for NGOs to maximize the benefits of involvement.

The involvement of people living with HIV/AIDS in the work of community-based HIV/AIDS organizations in developing countries can lead to an overall improvement in their health conditions, both at the psychological and physical level. However, involvement is not a miraculous cure for positive people; the range and intensity of beneficial effects is linked to the conditions of their involvement. As for the NGOs themselves, the involvement of people living with HIV/AIDS can make their programs more responsive to the needs of positive people, but only if their involvement is structured in a formal, ongoing manner.

These are the findings of the Diagnostic Study on the Involvement of People Living with HIV/AIDS in the Delivery of Community-Based Prevention, Care and Support Services, conducted between 1998 and 2001 by the Horizons Program in Burkina Faso, Ecuador, India, and Zambia.¹ Data were collected from 745 NGO service providers, clients, family members, health workers, policymakers, and community leaders,

both HIV-positive and HIV-negative.

People living with HIV/AIDS are involved with NGOs in four main ways:

- **Access.** People living with HIV/AIDS use the services of NGOs, such as medical care, counselling, or training. This is the most common way for positive people to be involved.
- **Inclusion.** People living with HIV/AIDS support the activities of the organizations, either as support staff or as occasional volunteers. For example, they may be requested to give testimonials from time to time, or they may be employed as helpers by NGOs. They play only a supporting role.
- **Participation.** People living with HIV/AIDS formally provide services on a regular basis, as employees or formal volunteers. For example, they may serve as outreach educators or counsellors.
- **Greater involvement.** People living with HIV/AIDS directly design services and manage organizations. They are program managers, directors, or trustees.

Impact of Involvement on the Quality of Life of People Living with HIV/AIDS

The involvement of people living with HIV/AIDS in the work of the NGOs can have both beneficial and harmful effects on the quality of life of the individuals involved. The beneficial effects include:

- **End to isolation.** Through peer support (eg, counselling, support groups) and other means, people living with HIV/AIDS usually meet other positive people when they join an NGO or use some of its services. They then realize that they are not the only ones living with HIV/AIDS, and can share problems and solutions with their peers.
- **Increased knowledge of HIV/AIDS, including treatments and better access to care.** Through their involvement with NGOs, people living with HIV/AIDS have access to more accurate information about various AIDS-related issues, including where they can access care, particularly good-quality care.
- **Better acceptance of HIV status and enhanced self-esteem.** Sharing experiences and having better access to information change the perception that positive people have of HIV infection. Often, this gives them more hope about their future. Positive people who are involved in service delivery or management feel that they are contributing to the community. For all these reasons, their self-esteem is higher and they tend to

cope better with their HIV infection.

- **Employment or material benefits.** In poor countries where unemployment is high and formal employment is very scarce, people living with HIV/AIDS who are employed by NGOs, or who receive some form of financial or material compensation, receive a more or less regular income that is essential to their well-being and that of their family. It enables them to buy food and medicines. In some cases, NGOs even provide free or affordable care to their HIV-positive service providers.
- **Behaviour change.** Another positive effect cited spontaneously by respondents in Zambia and Ecuador is a reduction in the number of sexual partners.
- **Increased acceptance by family.** In some cases, the family's perceptions may also change when family members have access to information and understand that HIV is not contagious. Family members also realize that their HIV-positive relative can be productive.

Respondents in all four countries reported drawbacks to the involvement of people living with HIV/AIDS in NGOs. The drawbacks varied depending on the activities carried out and the extent to which positive people were visible within the organization (ie, whether or not they were open about their status). The drawbacks include:

- **Stigmatization and discrimination.** Some people living with HIV/AIDS reported personal experiences of stigma and discrimination as a result of their visible involvement in delivering

services. Positive people who chose not to be visible said that the fear of being discriminated against was the main factor that stopped them from being open about their serostatus.

- **Depression.** When people living with HIV/AIDS who are asymptomatic care for other positive people who are already ill, they sometimes identify with the people they are caring for and, as a result, become depressed.
- **Burnout.** There is a high risk of burnout in organizations where there are few positive people actively involved. There are usually lots of demands on them, and it can be difficult to deal with this pressure.

Effects of Involvement for the NGOs

NGOs also experience both beneficial and harmful effects from the involvement of people living with HIV/AIDS. The beneficial effects include:

- **Changes in staff attitudes toward positive people.** NGO staff and management who previously interacted with people living with HIV/AIDS only as service users, have to confront their own perceptions and fears of HIV and positive people when these people become their colleagues. This usually leads to a more supportive environment for people within the NGO living with HIV/AIDS.
- **Improved understanding of issues affecting people living with HIV/AIDS.** By working with HIV-positive colleagues and sharing some of their problems, other service providers become more aware of the needs of posi-

tive people in general.

- **Integration of advocacy for the rights of people living with HIV/AIDS into the work of the organization.** In some cases, integrating the perspective of people living with HIV/AIDS into the organization has resulted in NGOs broadening their activities to include advocacy for the rights of positive people.
- **More relevant and personalized care and support services.** Many respondents reported that there is a high level of confidence between HIV-positive caregivers and their HIV-positive clients. This makes the NGO's services more responsive to the needs of people living with HIV/AIDS, especially in situations where many professional caregivers have judgmental attitudes and display discriminatory behaviour toward positive people. Also, the information provided by HIV-positive caregivers is seen as being more credible because they have gone through problems similar to what their clients experience.
- **More effective prevention activities.** The involvement of people living with HIV/AIDS in prevention outreach activities makes these activities more effective. First, it makes AIDS look more real in communities where there is still a lot of denial. Second, it increases the credibility of the information provided. Third, people are sometimes more encouraged to take an HIV test because they see that positive people are able to lead a normal life.
- **Increased credibility of the NGO.** NGOs that involve people living with HIV/AIDS in their organizations usually have more

credibility with the people who use their services, with the wider community, and with funders.

The harmful effects on the NGOs include:

- **Disruption of services.** Unfortunately, morbidity and mortality rates remain very high among people living with HIV/AIDS in countries where access to care and treatment is limited. This can have a negative impact on the sustainability of activities carried out by positive people working in NGOs. It can also threaten the sustainability of entire organizations when they are run by people living with HIV/AIDS.
- **Increased cost of training.** Another consequence of high mortality rates is the cost of training HIV-positive service providers when NGOs need to train people to replace those who die prematurely.
- **Higher benefit costs.** If the NGOs are providing care to their workers in the event of illness, they often incur additional costs because people living with HIV/AIDS are more likely to seek care on a regular basis than people without chronic infection.
- **Stigmatization.** NGOs that involve people living with HIV/AIDS may be seen as an organization of positive people. As a result, all members, whether HIV-positive or HIV-negative, may be stigmatized.
- **Conveying inaccurate information.** In the inclusive model of involvement, people living with HIV/AIDS who are used as occa-

sional volunteers are sometimes poorly trained. The risk of this type of involvement is that low-quality information is sometimes provided by these volunteers.

Recommendations

NGOs can take steps to boost the involvement of people living with HIV/AIDS in their organizations, to build a supportive environment for involvement, and to maximize the beneficial impact of involvement. These steps could include:

- **Developing non-discriminatory staff attitudes and policies.** Not all NGO staff are spontaneously tolerant of people living with HIV/AIDS, but attitudes can change through sensitization. NGOs should stress the need for all staff and volunteers to respect confidentiality.
- **Providing psychological support for HIV-positive service providers.** NGOs that provide support to their HIV-positive clients should also learn to support their service providers living with HIV. For people living with HIV/AIDS, peer support and professional psychological support should be seen as complementary approaches.
- **Building the skills of positive staff and volunteers.** NGOs should work with their positive staff and volunteers to identify training needs, and should develop orientation and training programs.
- **Providing treatment for HIV-positive staff and volunteers.** Making free or affordable treatment available will make the

involvement of people living with HIV/AIDS more sustainable, and will thus benefit both the NGOs and the HIV-positive staff and volunteers.

- **Providing referrals and opportunities to network.** Not all forms of involvement of positive people are always possible or even desirable in every NGO. NGOs should ensure that people living with HIV/AIDS who are involved with the organization are informed of services provided by other organizations, and are given opportunities to be involved with other NGOs. This would make it easier to achieve meaningful involvement of people living with HIV/AIDS in a larger number of organizations.

– Christophe Cornu

Christophe Cornu is an Associate Consultant with the International HIV/AIDS Alliance and was the Principal Investigator of the study. He can be reached at christophecornu@wanadoo.fr. This presentation was prepared with the support of Christopher Castle, who is a Program Associate with the Horizons Program, a global operations research program implemented by the Population Council in collaboration with the International Center for Research on Women, the Program for Appropriate Technology in Health, the International HIV/AIDS Alliance, Tulane University, Family Health International, and Johns Hopkins University. The International HIV/AIDS Alliance was the lead implementing agency for this study. Christopher Castle can be reached at ccastle@pcdc.org.

¹ A summary of the research is available on the website of the International HIV/AIDS Alliance via www.aidsalliance.org.

HIV Testing for Peacekeeping Forces: Legal and Human Rights Issues

In 2001, the United Nations Security Council established an Expert Panel to study the issue of whether the UN should institute HIV testing of peacekeeping personnel. This article, based on a 9 July 2002 presentation to the XIV International AIDS Conference (abstract TuOrG1173), reports on the findings of a paper prepared for the Expert Panel by the Canadian HIV/AIDS Legal Network. The paper examined whether it is permissible for the UN to implement mandatory HIV testing of its peacekeeping personnel, and whether HIV-positive UN peacekeeping personnel should be excluded or restricted from service on the basis of their HIV status or HIV disease progression. The article describes some of the court cases in which these issues have been considered; discusses the importance of analyzing such issues in the context of a human rights-based approach to the pandemic; and formulates a series of key principles for guiding UN decision-making. The article concludes that a policy of mandatory HIV testing for all UN peacekeeping personnel cannot be justified on the basis that it is required in order to assess their physical and mental capacity for service; that HIV-positive peacekeeping personnel cannot be excluded from service based on their HIV status alone, but only on their ability to perform their duties; and that the UN cannot resort to mandatory HIV testing for all UN peacekeeping personnel to protect the health and safety of HIV-negative personnel unless it can demonstrate that alternatives to such a policy would not reduce the risk sufficiently. In the end, the Expert Panel unanimously rejected mandatory testing and instead endorsed voluntary HIV counselling and testing for UN peacekeeping personnel.

Introduction

In Resolution 138, adopted on 17 July 2000, the Security Council expressed “concern at the potential damaging impact of HIV/AIDS on the health of international peacekeeping personnel, including support personnel.”¹ The Joint United Nations Programme on HIV/AIDS (UNAIDS) convened a strategy meeting in Sweden in December 2000 to address the broad array of issues concerning HIV/AIDS and peacekeeping. Subsequently, UNAIDS, in collaboration with the UN Department of Peacekeeping, established an Expert Panel on HIV Testing in UN Peacekeeping

Operations to analyze and formulate a comprehensive position on the issue of HIV testing. The Expert Panel convened in Bangkok in late 2001.²

A paper was commissioned to contribute to the deliberations of the UNAIDS Expert Panel.³ The main questions addressed by the paper are as follows:

- Is it permissible for the UN to implement mandatory HIV testing of its peacekeeping personnel?
- Can HIV-positive UN peacekeeping personnel be excluded or restricted from service on the

basis of their HIV status or HIV disease progression?

These two questions are closely linked because, as an employer, the UN is only entitled to require information about the HIV status of its peacekeeping personnel or applicants for service (by mandatory testing or otherwise) if it can legitimately use that information to make employment-related decisions.

Court Judgments

There are a few court cases in which these questions have been considered in a military context. The following is a brief description of the most important cases:

- *N v Minister of Defence* (Namibia):⁴ At issue was the ability of the Namibian Defence Force to refuse to enlist an applicant for service on the basis of his HIV-positive status alone. The appli-

The UN is only entitled to require information about the HIV status of its peacekeeping personnel if it can legitimately use that information to make employment-related decisions.

cant’s challenge before the Labour Court of Namibia succeeded.

- *Hoffmann v South African Airways* (South Africa):⁵ At issue was the ability of South African Airways (SAA) to refuse to

employ an HIV-positive recruit as a cabin attendant solely on the basis of his HIV status. The applicant's challenge failed initially, but succeeded on appeal to the Constitutional Court of South Africa.⁶

- *A v Union of India* (India):⁷ At issue was the ability of the Indian Navy to refuse to re-engage a crew member in the Submarine Branch solely on the basis of his HIV status. The crew member's challenge failed before the High Court of Judicature at Bombay.
- *X v Commonwealth of Australia* (Australia):⁸ At issue was the ability of the Australian Defence Force to terminate the service of an enlisted soldier solely on the basis of his HIV status. The soldier's challenge succeeded before a human rights tribunal, was returned to the tribunal for a rehearing, and ultimately resulted in a settlement on undisclosed terms.
- *Thwaites v Canada* (*Canadian Armed Forces*) (Canada):⁹ At issue was the ability of the Canadian Armed Forces to terminate the service of an enlisted soldier on the basis of his HIV-positive status and related disease progression. The soldier's challenge succeeded before a human rights tribunal and was upheld on review by a court.

The Importance of a Human Rights-Based Approach to HIV/AIDS

Global public health and other experts have long emphasized the need to protect, rather than limit, the human rights and fundamental freedoms of people with HIV/AIDS (and those vulnerable to HIV infection),

and to integrate them into society to the fullest extent possible, as the most effective means of preventing

A human rights-based approach is the most effective means of preventing the spread of HIV and of mitigating the social and economic impact of AIDS.

the spread of HIV and mitigating the social and economic impact of the pandemic.

This is generally referred to as a "human rights-based approach" – ie, an approach that protects, respects, and fulfils (rather than restricts) human rights.¹⁰ The International Guidelines on HIV/AIDS and Human Rights provide a framework for a human rights-based approach by outlining in concrete and practical terms how human rights standards apply in the context of HIV/AIDS.¹¹ A human rights-based approach is important because it is the most effective means of preventing the spread of HIV and of mitigating the social and economic impact of AIDS, and because it is morally right. The importance of adopting a human rights-based approach to HIV/AIDS has been affirmed by institutions such as the UN High Commission for Human Rights, UNAIDS, the World Health Organization, and the International Labour Organization.

The fundamental importance of human rights, and the preponderance of expert opinion that protection, rather than restriction, of human rights is the most effective means of

protecting the public health from HIV transmission, mean that particularly serious reasons would have to be put forward by the UN before measures that infringe upon the human rights of HIV-positive peacekeeping personnel could be considered acceptable.

Relevant provisions in the Charter of the United Nations, the Universal Declaration of Human Rights, and other UN instruments demonstrate a commitment on the part of the UN to act in conformity with international human rights law. In particular, in the Declaration of Commitment on HIV/AIDS,¹² the UN General Assembly affirmed its commitment to provide leadership in the protection of human rights, including in the context of the employment of people living with HIV/AIDS.

Principles Derived from the Right to Equality of Treatment in Employment

An analysis of the elements of human rights law that protect the right of people living with HIV/AIDS to equality of treatment in employment gives rise to the following key principles for guiding UN decision-making with respect to service by peacekeeping personnel.

- HIV-positive peacekeeping personnel are entitled to equality of treatment in employment. This includes protection against discrimination and positive assistance from employers.
- A decision to exclude or restrict UN peacekeeping personnel from service is not discriminatory where the inability to perform the inherent requirements of the job is an issue.
- The UN's purpose and underlying

ing reasons in considering whether HIV status (or a given stage of HIV disease progression) should be identified as an inherent job requirement for UN peacekeeping service must not be founded on prejudice or stereotype, but rather on sound employment and public health practices.

- The mental and physical capacity of peacekeeping personnel to perform their duties, the health and safety of HIV-positive peacekeeping personnel, and the health and safety of others (ie, HIV-negative peacekeeping personnel) – all relate to the operational effectiveness of peacekeeping missions and, as such, are legitimate subjects of UN concern.
- In order for HIV status (or a given stage of HIV disease progression) to be characterized as an inherent job requirement of UN peacekeeping service, the UN would have to establish that it is *reasonably necessary* to address the stated concern. To be reasonably necessary:
 - the UN must show that the risk assessment is based on the most *authoritative and up-to-date medical, scientific, and statistical information* available, and not on impressions, assumptions, speculations or unfounded generalizations;
 - the risk assessment must be made on an *individualized* basis;
 - the identified risk must be *significant*. Whether the risk is significant must be measured on a comparative basis, in the context of a particular job, and against other risks presented by UN peacekeeping service. If risks of comparable magni-

tude are acceptable in the work environment, risks posed by an HIV-positive person cannot be considered significant. This “relative risk” standard recognizes that human endeavours are not totally risk free and that some risk is therefore tolerable; and

- the UN must establish that the requirement is *not disproportionate* – ie, that to address the concern at issue, there are no other means less prejudicial to the rights to equal treatment of HIV-positive peacekeeping personnel. This requires the UN to search for reasonable alternatives before resorting to the imposition of a blanket exclusionary policy.

Principles Derived from the Right to Privacy

An analysis of the elements of human rights law that protect the right of people living with HIV/AIDS to privacy of information about their HIV status gives rise to the following key principles for guiding UN decision-making with respect to mandatory HIV testing of peacekeeping personnel.

- UN peacekeeping personnel are entitled to privacy of information about their health, including, in particular, their HIV status. This privacy may be infringed only in limited circumstances.
- The UN bears the burden of justifying infringements on this right to privacy.
- The physical and mental capacity of UN peacekeeping personnel to perform their duties, the health and safety of HIV-positive peacekeeping personnel, and the health and safety of others, all relate to

the operational effectiveness of UN peacekeeping missions. They are legitimate subjects of UN concern and are thus possible sources of limitations on privacy rights.

- The public health importance of protecting the human rights and fundamental freedoms of HIV-positive peacekeeping personnel requires that the least intrusive, least restrictive measures be used to address the foregoing UN concerns.
- Mandatory employment-related medical examinations to assess the fitness of employees for the inherent requirements of their jobs are permissible.
- A stringent approach to the protection of privacy requires that the UN demonstrate that the HIV testing of UN peacekeeping personnel, as part of such medical examinations, is *necessary*. To be necessary:
 - if the objective of HIV testing is to respond to and identify the problem or risk, the risk must be *real* rather than hypothetical, and it must be *significant*;
 - HIV testing must be the *most effective* means of addressing the problem, in that alternatives would not suffice; and
 - the UN’s arguments in this regard must be supported by concrete evidence.
- If a requirement for HIV testing can be justified, it must be implemented in a minimally intrusive manner. In particular:
 - the informed consent of peacekeeping personnel must be sought before HIV testing is carried out; and
 - a refusal to give informed consent must be respected in its

entirety, and cannot be circumvented by surrogate forms of HIV testing.¹³

What Conclusions Can Be Drawn?

Physical and mental capacity for peacekeeping service

A policy of mandatory HIV testing for all UN peacekeeping personnel could not be justified on the basis of the necessity to assess physical and mental capacity for service. This is because HIV-positive status alone is not determinative of a lack of capacity for service. HIV-positive individuals who are asymptomatic or symptomatic may nonetheless function at full capacity. HIV testing should only be required when, in the opinion of a qualified medical practitioner, it becomes necessary to assess physical and mental capacity for peacekeeping service.

HIV-positive peacekeeping personnel cannot be excluded from service, and HIV-positive applicants for peacekeeping service cannot be refused employment, based on their HIV status alone. The UN must undertake appropriate and individualized assessments of the physical and mental capacity of HIV-positive people so that employment-related decisions can be made on the basis of real, and not perceived, facts.

A categorized approach to assessment and restriction from service – ie, downgrading all those with symptomatic HIV infection – regardless of the nature, extent, and impact of such symptoms upon the individual – should be avoided. The UN must make reasonable adjustments and/or provide reasonable accommodation to HIV-positive peacekeeping personnel to enable them to continue to serve as long as possible.

Health and safety of others

The ability of HIV-positive UN peacekeeping personnel (or applicants for service) to serve with reasonable safety to others is a legitimate subject for concern on the part of the UN in relation to its operational effectiveness.

Beyond this general principle, however, the authorities are not prescriptive. In general terms, it is clear that before the UN could resort to a blanket rule of mandatory HIV testing for UN peacekeeping personnel, or to exclusion or restriction from service, in order to protect the health and safety of others:

- it must establish that reasonable alternatives to such a rule (including, but not limited, to the ability to accommodate people so as to lessen the risk) do not reduce the risk to the point that it is of comparable magnitude to other risks presented by peacekeeping service; and
- it must do so on the basis of the most authoritative and up-to-date medical, scientific, and statistical information available.

Conclusions of the UN Expert Panel

The Expert Panel on HIV Testing in UN Peacekeeping Operations 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 compre-

hensive and integrated package of HIV prevention and care services.

– presented by Ralf Jürgens

Ralf Jürgens is Executive Director of the Canadian HIV/AIDS Legal Network. He can be reached at ralfj@aidslaw.ca. Lead author of the paper on which this article is based is Lori Stoltz, who was President of the Network when the paper was written. The third contributing author was David Patterson, Director of International Programs and Capacity Building for the Network.

¹ S/RES/1308 (2000) 17 July 2000, OP I and 5.

² See UNAIDS. Report of the UNAIDS Expert Panel on HIV Testing in United Nations Peacekeeping Operations. 28-30 November 2001, Bangkok, Thailand. Available via www.unaids.org/publications/documents by clicking on "Uniformed Services."

³ The full background paper on "Mandatory HIV Testing of UN Peacekeeping Forces: Legal and Human Rights Issues" prepared by the Canadian HIV/AIDS Legal Network for UNAIDS is available via www.unaids.org/publications/documents by clicking on "Uniformed Services."

⁴ Labour Court of Namibia, delivered 2000 05 10, Case No. LC 24/98.

⁵ CCT 17/00, Constitutional Court of South Africa (28 September 2000).

⁶ Although this case did not arise in a military setting, it is included because the rationale advanced by SAA in support of its position was similar to arguments that have been put forward in the military setting.

⁷ Writ Petition No. 1623 01 2000, High Court of Judicature at Bombay (28 November 2000).

⁸ [1999] HCA 63.

⁹ [1993] CHR D No. 9 (7 June 1993); affirmed *Canada (Attorney General) v Thwaites*, [1994] 3 FC 38 (TD).

¹⁰ UN Office of the High Commissioner for Human Rights. A Human Rights-Based Approach to HIV/AIDS. UN General Assembly Special Session on HIV/AIDS, 25-27 June 2001, at para 4.

¹¹ The International Guidelines were published jointly by the Office of the High Commissioner for Human Rights and UNAIDS in February 1998 and have since been used by governments, human rights institutions, UN agencies and bodies, non-governmental organizations, and people living with HIV/AIDS, as a tool for HIV/AIDS and human rights training, policy formation, the development of HIV/AIDS related legislation, and advocacy. The Guidelines are available via www.unaids.org.

¹² Adopted by the General Assembly in June 2001. Available on the website of UNAIDS at www.unaids.org/UNGASS/index.html.

¹³ The standard form of testing for HIV involves detecting the presence of HIV antibodies in the blood. Examples of surrogate testing are CD4 count measurement and P-24 antigen testing.

HIV/AIDS-Related Stigma and Discrimination: A Conceptual Framework

Only if we understand where HIV/AIDS-related stigma and discrimination come from, and how they are connected to broader social inequalities and the denial of fundamental human rights, can we develop effective strategies to combat them. This article is a much-condensed version of a keynote presentation given at “Meeting the Stigma Challenge: New Paradigms for Civil Society,” a satellite meeting held in Barcelona on 8 July 2002, and sponsored by the Joint United Nations Programme on HIV/AIDS (UNAIDS). The presentation described the conceptual framework underpinning the 2002-2003 World AIDS Campaign, whose theme is “HIV/AIDS-Related Stigma and Discrimination,” and whose slogan is “Live and Let Live.” In this article, Peter Aggleton provides a conceptual overview of the relationship between the stigma and discrimination associated with HIV and AIDS and the human rights violations that ensue from them, with the goal of demonstrating the interconnectedness of these concerns. He also provides some examples of concrete steps that can be taken to counter the stigma, discrimination, and human rights violations.

Introduction

HIV/AIDS-related stigma and discrimination are the greatest barriers to preventing the spread of HIV, to providing adequate care, treatment, and support, and to alleviating the impact of the disease. To address HIV/AIDS-related stigma and discrimination, we need to do three things: to prevent HIV/AIDS-related stigma from forming; challenge HIV/AIDS-related discrimination where it occurs; and challenge and redress the human rights violations that follow from such discrimination.

Causes and Effects of Stigma

In the context of the global epidemic, the causes of stigma are many. They include:

- lack of understanding of HIV/AIDS;
- myths about the transmission of HIV;

- prejudice stemming from initial reports of infection among socially marginalized groups;
- lack of availability of treatments for HIV;
- irresponsible media reporting;
- the fact that AIDS is incurable;
- social fears about sexuality; and
- fears relating to illness and death.

Stigma is a process, not a thing. Stigmatization describes a process of devaluation that involves the identification of “undesirable differences,” the creation of “spoiled identities,” processes of distancing and of personal and societal denial. It is also the process by which people place themselves outside the epidemic, seeing themselves as somehow protected and quite unlike those who are stigmatized.

Stigma is harmful because it can lead to feelings of shame and guilt on the part of people living with

HIV/AIDS. It can cause individuals to become isolated, and it can cause them to do things, or omit to do things, that harm others or deny others services or entitlements. People living with HIV/AIDS have been:

- segregated or ill-treated in schools and hospitals;
- refused employment or offered inferior types of employment;
- denied the right to marry and found a family;
- required, when returning to their national country, to submit to an HIV test;
- denied the right to return to their national country on suspicion of being HIV-positive;
- denied visas or permission to enter when seeking to travel to other countries;¹ and
- attacked, wounded, or killed because of their seropositive status.

While HIV/AIDS-related stigma is immediate, its origins lie deep within society. HIV/AIDS-related stigma plays into, reinforces, and reproduces existing social inequalities. Therefore, tackling stigma involves dealing not only with its surface manifestations, but also its roots. Over twenty years of experience has shown that there are clear links between HIV/AIDS-related stigma and discrimination and sexual, gender, race, and class relations and divisions in society. Too frequently, women, sex workers, homosexuals, and black people have been blamed for causing the epidemic. AIDS is widely perceived as disease of “others,” of “outsiders.” This is reflected in seemingly contradictory sets of statements such as “AIDS is a Western disease” and “AIDS is an African disease;” or “AIDS is a woman’s disease” and “AIDS is caused by men.”

The Importance of Human Rights

Stigma, discrimination, and human rights violations form a vicious cycle. Stigma causes discrimination; discrimination leads to violations of human rights; human rights violations legitimize stigma; and the stigma leads to more discrimination.

Freedom from discrimination is a fundamental human right founded on principles of natural justice that are universal and perpetual. Recent resolutions of the United Nations Commission on Human Rights make it clear that the term “or other status” in the various international human rights instruments should be interpreted to cover health status, including HIV/AIDS; and that discrimination on the basis of AIDS or HIV status, actual or presumed, is prohibited by existing international human rights standards.² Therefore, discrimination against people living with HIV/AIDS, or those believed to be infected, is a clear violation of their human rights.

Responding to Stigma and Discrimination

In developing a response to HIV/AIDS-related stigma and discrimination, we first need to think carefully about what HIV/AIDS-related stigma and discrimination are, where they come from, and what they do. Then we need to understand the connections between HIV/AIDS-related stigma and discrimination, broader inequalities and injustices, and the denial of human rights and fundamental freedoms. Finally, we need to take action, with the objective of preventing, challenging, and redressing stigma, discrimination, and human rights violations.

The United Nations Declaration of Commitment on HIV/AIDS³ is an important tool around which to organize our work. We need to act in each

of the key areas identified in it:

- education;
- inheritance;
- employment;
- social and health services;
- prevention;
- support and treatment;
- information; and
- legal protection.

Examples of concrete steps that should be considered are:

- awareness campaigns to help people understand the unfairness and injustice of stigma and discrimination;
- good-quality education in and out of schools to provide people with the facts and to change attitudes;
- ensuring that treatment, prevention, care, and support services are accessible to all;
- leadership and commitment on the part of politicians, church leaders, sports personalities, movie stars, and others to challenge HIV-related discrimination, spearhead public action, and act against discrimination;
- involving people living with HIV/AIDS fully in the response to the epidemic;
- monitoring human rights violations, and ensuring that people are able to challenge discrimination and receive redress through national administrative, judicial, and human rights institutions;
- training for health-care workers and others in situations where stigmatization and discrimination have been found to be prevalent; and
- activism and grass-roots organizing by people living with, and affected by, HIV/AIDS.

Conclusion

In order to successfully tackle the stigma and discrimination associated

with HIV/AIDS, we need to understand its nature, and its clear links to the violation of human rights. Only a concerted and multi-pronged effort, acting simultaneously at several levels, will deal with the problem.

Ultimately, a broad-based programmatic effort, involving all sectors of society, will be needed to reduce the negative responses to which the epidemics has given rise. People living with HIV/AIDS have a central role to play in this work – as advocates, policymakers, program planners, friends, and colleagues. But the responsibility for action must be shared, and it is the actions of those who stigmatize and discriminate that must be challenged. The application of a rights-based framework has the capacity to do just this.

– Peter Aggleton

Peter Aggleton is the Director of the Thomas Coram Research Unit at the Institute of Education, University of London. The presentation on which this article is based was developed from work undertaken by Peter Aggleton, Richard Parker (Columbia University, New York), and Miriam Maluwa (UNAIDS) to support the 2002-2003 World AIDS Campaign. Their work is described in a publication entitled *A conceptual framework and basis for action: HIV/AIDS stigma and discrimination*, available on the UNAIDS website at www.unaids.org/publications/documents/human/JC781-ConceptFramew-E.pdf.

¹ The United States Department of State has developed a list that highlights about 60 countries that require HIV tests, and conditions that are applied. Available on the net at <http://travel.state.gov/HIV/testingreqs.html>. See also: JY Carlier. *The Free Movement of Persons Living with HIV/AIDS*. European Union HIV/AIDS Programme in Developing Countries. Luxembourg: European Commission, 1999. See also: Deutsche AIDS Hilfe and AIDS Info Docu Schweiz, Quick Reference. Travel and residence regulations for people with HIV and AIDS (3d ed). Berlin, December 2001. The text is accessible in German at www.aidsnet.ch/immigration/d and in French at www.aidsnet.ch/immigration/f.

² United Nations Commission on Human Rights, Resolutions 1999/49, 2001/51, 2002/47. Available on the Commission's website via www.unhcr.ch/.

³ Adopted by the United Nations General Assembly in June 2001. Available on the website of the UNAIDS at www.unaids.org/UNGASS/index.html.

Barcelona 2002: Abstracts on Legal, Ethical, and Human Rights Issues

There were over 230 abstracts at the XIV International Conference on AIDS dealing with legal, ethical, and human rights issues, compared with about 140 at the XIII International Conference on AIDS at Durban in 2000 and about 80 at the XII International Conference on AIDS at Geneva in 1998. The topics addressed in the abstracts ranged from promoting sexual health and sexual rights among young people to the ethics of HIV research, and from models of HIV advocacy to the automatic exclusion of HIV-positive immigrants. Only a small number of abstracts can be included in this special issue of the *Review*. The following abstracts have been chosen because, together with the other articles in this special issue, they provide a representative sample of the many legal, ethical, and human rights topics addressed at the Conference. Two of the abstracts deal with monitoring human rights interventions, and one with the absence of such interventions. One abstract deals with barriers to anti-discrimination legislation. Two describe the use of the law in advancing the response to HIV/AIDS. Two others deal with drug use, one with the assessment of drug policies and the other with the establishment of a safe injection facility. Two abstracts address gender issues, one vaccine research, and one prisons. Of the 12 abstracts presented here, eight relate to developing countries. Other abstracts from the XIV Conference are available on the Conference website via www.AIDS2002.com.

Abstract E1023: Indian Laws Exacerbate the Vulnerability of Women to HIV

Background: Identifying impediments in Indian law and legal procedure allow for a comprehensive understanding of the social and ethical issues that heighten the vulnerability of women to HIV, and highlight areas where legal reforms are required. A study of about 70 legal cases was undertaken in order to understand the legal issues faced by women living with HIV/AIDS.

Method: Analysis of the legal cases handled by the Lawyers Collective HIV/AIDS Unit between 1998 and 2001 was undertaken. The analysis

categorized female clients living with HIV/AIDS according to age and marital status. Legal issues were identified and categorized in terms of family issues, economic dependence, property rights, maintenance, custody of children, discrimination in health care, consent and confidentiality, and criminal law relating to harassment.

Results: The analysis found that most women fell within in the age group of 18 to 30, and that more than 50 percent were economically dependent and unemployed widows. Significantly, maintenance sought by women from husbands or in-laws has been a prominent issue. The realities and social circumstances relating to HIV have perpetuated, exacerbated, and heightened the inequalities that render

women homeless and destitute. Unfortunately, Indian personal laws continue to perpetuate gender inequality and are ill equipped to resolve the various difficulties faced by women in the context of the social circumstances of HIV/AIDS.

Conclusions: There is an urgent need to reform laws that affect women, and to empower them through the provision of a strong system of structural legal support. It is also imperative that personal law reform be undertaken with a view to meeting the gender-specific needs of women affected and infected by HIV/AIDS.

Presented by Nidhi Dubey, Lawyers Collective HIV/AIDS Unit, 7/10, Botawalla Building, 2nd Floor, Horniman Circle, Fort, Mumbai 400023, India. Email: aidslaw@vsnl.com.

Abstract G4232: Community Participation in HIV-Vaccine Research in Brazil

Issues: In Brazil, community members have limited experience in following clinical research. However, the fact that we are entering a historical period in which the rhythm of HIV-vaccine research will intensify represents a unique opportunity to expand community leadership and involvement with the issue.

Description: In Rio de Janeiro, Brazil, an HIV vaccine trials unit has been developing a Community Education Plan for the purpose of creating a supportive community environment for the development of HIV-vaccine research and of establishing a community participation model for investigations of this nature. The Plan includes the implementation of capacity build-

ing for community leaders, the creation of the first Community Advisory Board in Brazil, the development of a media plan, the creation of educational materials, and the implementation of recruitment outreach activities.

Lessons learned: Community leaders play a key role in ensuring the relevance of HIV-vaccine research to affected communities and in supporting the recruitment of study volunteers. A well-informed community helps ensure the ethical quality of proposed research, and thereby contributes to the advancement of research initiatives.

Conclusions: HIV-vaccine research must be combined with an intense educational effort that seeks to minimize the difficulties inherent in recruiting volunteers, to deconstruct myths related to research, and to build an equal partnership with the affected community. Community education actions specifically planned for Brazil can contribute significantly to the construction of a collaborative process between the community movement and the scientific community. A Community Education Plan could expand community involvement in HIV-vaccine issues.

Presented by Mônica Souza, C Yoshida, G Santos, M Schechter, O Valente, Projeto Praça Onze, Rio de Janeiro HVTU, Rua Gavião Peixoto, 355/1603. Niterói-RJ. Brazil. CEP. 24230093, Brazil.

Abstract G8237: The Anti-Discrimination Advocacy Project: Bridging Theory and Practice

Issues: Despite inroads that have been made in the area of discriminatory practice and rights protection in Australia, the systemic difficulties in

implementing human rights legislation have proved disheartening. Few complaints are lodged in a climate of high levels of homophobic and HIV-related discrimination. The extent of the human, public health, and societal impact of HIV/AIDS gives added incentive to ensure anti-discrimination laws and systems are effective. Due to the role that social environments play in supporting HIV-prevention efforts, this is relevant to the protection of human rights of those infected and of those most at risk of infection.

Description: With the goals of identifying barriers to the effective implementation of discrimination legislation, and of developing strategies to overcome such barriers, the Anti-Discrimination Advocacy Project was established through partnership with governmental and non-governmental agencies. The project focuses on two main factors: one involves the importance of the legal dimension of human rights and the other is based on the fact that such legal protection necessarily exists within, and is vitally affected by, a broader non-legal context.

Lessons learned: The two objectives of community action are to increase the knowledge and skills of community workers to maximize the ability of individuals to take action in response to discrimination, and to strengthen the capacity of the community sector to advocate for improvements to anti-discrimination remedies and for law reform.

Conclusions: By taking a comprehensive approach to health, the Anti-Discrimination Advocacy Project points to community as an effective site for intervention. This is not to undervalue the importance of a supportive legal framework, but to suggest that action should move beyond

sole reliance on legal initiatives toward building resistance to discrimination in communities.

Presented by Michael Reid, AIDS Council of New South Wales, Southern Cross University & Anti-Discrimination Board of New South Wales, P O Box 6063, South Lismore, NSW, 2480, Australia. Email: acon@acon.org.au.

Abstract F1167: The First Injection Room in Geneva: A Marathon

Issues: An injection room increases the impact of harm reduction by reducing the risks of HIV and hepatitis transmission caused by poor injecting conditions. It also offers to injection drug users the possibility of finding a place where they will be listened to and offered information, the means of prevention, or a coffee. It reduces the social impact of drug use in the neighbourhood. It is also highlights a health problem (drug use) and gives it official recognition. Setting up an injection room takes time because there are divergent missions that public authorities must conceal: prevention, treatment, and harm reduction, but also repression.

Description: In late 2001, the Groupe sida Genève opened the first injection room in Geneva after long negotiations with political, police, health, and social agencies. Years of successful harm-reduction programs (eg, a needle-exchange bus in operation since 1991) have shown that to increase the impact of such programs – which drastically reduced HIV infections among injection drug users – we had to work on the injecting conditions, a weak point where many are at risk. We went to our local government to submit an experimental project involving the establishment of an injection room. Initially turned down, the project was approved with

support by all health and social agencies in Geneva. A pilot group composed of representatives of the agencies and the Geneva police has been appointed.

Lessons learned: It takes time to achieve major steps to implement “sensitive” projects such as injection rooms. Such projects can only work if all the partners, including people who live in the neighbourhood, are convinced of the need for it.

Conclusions: It is too early to provide recommendations concerning the room itself. However, our experience clearly shows that a pragmatic approach that involves putting the individual – the drug user – in the middle of the process is the only valid solution. It also helps to bring dignity to drug users by not seeing them as criminals, but rather as individuals who have rights that need our support.

Presented by Florian Hübner, C Berthet, C Mani, Groupe sida Genève, Geneva, Switzerland. Email: florian@hivnet.ch.

Abstract: G6909: Absence of Effective HIV/AIDS and Human Rights Interventions in Zambia: A Hindrance to Development

Issues: HIV/AIDS is a health and development crisis of epidemic proportions. However, very few countries have addressed (at least in practice) the legal issues raised by the pandemic. The combination of interventions must include the promotion and protection of the rights of people living with AIDS. This improves the ability of prevention programs to reach infected and vulnerable populations.

Description: Research reveals that there are no specific Zambian laws

on HIV/AIDS. Therefore, for those that have been discriminated against, there is no system for redress. Human rights is a fairly new concept in the country: HIV/AIDS and human rights is even newer. HIV/AIDS interventions have been limited to awareness about the major modes of transmission and about how not to contract the virus. Little has been said about stigma and discrimination. Most people do not get tested, and when they do, they remain silent about their serostatus. Hospitals have no HIV drugs, or even medications for simple ailments. The price of drugs is beyond the reach of even the upper-middle class, so most people just die in their homes. The situation is deteriorating so fast that no development efforts can keep up with these trends.

Lessons learned: HIV/AIDS human rights interventions must reach the grass roots if any development is to take place in the Third World. Neglect of human rights abuses contradicts one of the core objectives of development, which is to eradicate or reduce inequality. Development is about guaranteeing and upholding the rights of people.

Recommendations: The recommendations for Zambia are: (a) to conduct research into the legal issues raised by HIV in Zambia in order to identify, prioritize, and document pertinent issues; and (b) promote community advocacy to create awareness about not only modes of transmission, but also human rights and the rights of people with HIV/AIDS.

Presented by Malala Sakufiwa, Zambian AIDS-Law Research and Advocacy Network, P.O. Box 7, Chilanga, Zambia; and David Patterson, Canadian HIV/AIDS Legal Network, Montréal, Canada.

Abstract G1124: Rapid Assessment of Drug and Harm- Reduction Policies in Eastern Europe and the Former Soviet Union

Issues: Efforts to reduce the spread of HIV and other bloodborne diseases among injection drug users in Eastern Europe and the former Soviet Union are hampered by poor access to information on laws and policies crucial to drug use and harm reduction. Local public health and harm-reduction workers encounter rapid changes in the drug trade, the HIV epidemic, and in the legal, social, and economic environments.

Description: This project developed a rapid policy assessment tool (RPAT) for assessing law, policy, and other aspects of the HIV and drug-use epidemics. Local legal and harm-reduction personnel work together to collect data on formal law and policy, actual practice (including relevant constraints on resources), law enforcement practices, and key informants’ perspectives on barriers to harm-reduction measures. RPAT information is posted on the web in the form of country profiles, which can be used to identify opportunities for policy change.

Results: We report the results of a preliminary analysis in 25 countries and training in five countries. The 25 countries exhibit differing documented levels of HIV and drug use; injection drug users lead the epidemic in most countries. Laws may not formally prevent harm-reduction activities, but policy, practice, and resource constraints make effective harm reduction difficult and conflict with recommended best practices for HIV prevention. Although syringe possession is legal in many countries,

possession exposes injection drug users to arrest for drug-related crimes. Methadone is often illegal. Laws protective of individual rights and laws providing a “right” to medical or drug treatment often are not applied.

Conclusions: Rapid-assessment tools facilitate collection of policy data in areas where such data are poorly accessible. Policy data should be integrated into HIV-prevention research, policy, and advocacy at all levels.

Presented by Zita Lazzarini,¹ S Burris,² P Case,³ D Abrahamson,⁴ and J Welsh.²

¹University of Connecticut Health Center, Farmington CT, United States; ²Temple University Law School, Philadelphia PA, United States; ³Harvard Medical School, Boston MA, United States; ⁴Lindesmith Center, San Francisco CA, United States.

Abstract G5560: Auditing Human Rights in the Context of HIV/AIDS

Background: A pilot legal rights audit was conducted in the state of New South Wales in Australia to measure the extent of implementation of the International Guidelines on HIV/AIDS and Human Rights.

Description: The instrument consists of ten quantitative indicators to assess whether general international obligations as reflected in specific commitments have been complied with at the domestic level in one area: the law. The justiciable rights being measured include the rights to health, privacy, non-discrimination, liberty, education, information, and scientific advancement. Extralegal implementation is not measured, nor is the actual enforcement of formal laws, but the audit is a necessary and complementary first step. Law can provide real opportunities for redress (eg, access to treatment).

Lessons learned: Tripartite participation of independent experts, community groups, and governments is essential to a transparent accountability process. The snapshot results of the audit are useful for advocates who highlight areas of best practice (eg, anti-discrimination and needle exchange laws) and stimulate law reform in areas of concern (eg, voluntary testing). By charting possible progress, the audit could help sharpen the dialogue before UN treaty-monitoring bodies that consider country reports.

Conclusions: The pilot needs to be extended to the rest of Australia before it can be adapted for other countries. The most valuable use of the instrument is in developing countries, where the epidemic is concentrated and human rights needs are greatest. The instrument could be further refined and simplified, thus providing an evaluation tool that can be linked to other vital fields of research (eg, epidemiology). Such repeated empirical studies could provide causal evidence that promotion and protection of human rights have a positive force on the epidemic, by preventing the infection of vulnerable people, by reducing the impact of infection, and by enabling civil society to respond effectively.

Presented by Helen Watchirs, Australian National University, 32 Roebuck Street, Red Hill, ACT 2603, Canberra, Australia. Email: watchirsh@law.anu.edu.au.

Abstract G1419: Anti-lesbian Rape, HIV, and the Human Rights of South African Lesbians

Issues: Sexual violence confirms the vulnerability of already marginalized groups, and creates new forms of vulnerability and marginalization. The rape crisis in South Africa, and

its role in the HIV/AIDS pandemic, cannot be addressed without understanding how gender and sexual norms – and social punishment for those who infringe them – function in local communities.

Description: South Africa has the world’s highest rate of reported rape. A total of 2.3 million women and 1.8 million men are HIV-positive. Socioeconomic inequality, along with patriarchal gender and sex roles, subject women to high rates of sexual violence, thereby magnifying the rise of HIV transmission. Many women are targeted for rape because of their actual or presumed sexual orientation. Because of stigma associated with both rape and homosexuality, these cases go largely unreported. Thus, HIV/AIDS policy has failed to recognize the impact of the epidemic upon lesbians. This paper examines the range of state responsibilities in addressing sexual violence against lesbians in the HIV context. It shows how South Africa’s constitution promises opportunities for both prevention and remedy that have not yet been fulfilled.

Lessons learned: Gender roles, unemployment, domestic values (and violence) that impede women’s independence, and the housing and transportation crises in South Africa, all affect lesbians. Approaches to these issues must be weighed for their impact on health and HIV, and mechanisms must weigh the impact of HIV/AIDS policy on gender- and sexuality-related rights.

Recommendations: In implementing the Constitution’s equality clause, South Africa must sensitize criminal justice and health-care systems to issues of sexuality and gender. A discrimination-based approach, however, offers only partial protection for lesbians. Constitutional protections

for economic and social rights must be implemented, and unemployment, housing, and transportation crises addressed, to ensure respect for women's space and freedom of movement.

Presented by Kagendo Murungi, International Gay and Lesbian Human Rights Commission, c/o Human Rights Watch, 350 Fifth Avenue, 34th Floor, New York, NY 10118, United States; and NP Mabele, Positive Women's Network, Pretoria, South Africa.

**Abstract G1173:
Legal Advice and
Support Project: Fighting
for PWA Rights and for
the Elaboration of AIDS
Public Policies**

Issues: Those affected by the epidemic in Brazil are mostly low-income people, sometimes living in extreme poverty. These people, who mostly have elementary education only, do not know their basic rights. They represent the target audience of the Legal Advice and Support Project, operated by Grupo Pela VIDDA-RJ.

Description: This free legal service is part of a strategy to consolidate the rights of people with AIDS and to promote the elaboration of efficient public policies, in order to produce a response at the national level that will benefit a larger number of individuals. Since 1989, the project has reached, free of charge, over 6500 people, and it has currently more than 300 legal proceedings underway. Moreover, the project has established partnerships with various sectors, such as universities and companies, and has undertaken training for health-care professionals. These partnerships have resulted in a wider range of benefits for the affected

public, clarifying their rights and encouraging discussion on human rights issues in public health.

Results and lessons learned: The many victories in the Brazilian courts concerning access to medication, guarantee of care by private insurance, state responsibility on the quality control of blood banks, etc, have enormously influenced government attitudes toward these issues. Our proceedings regarding access to treatment helped to bring about the inclusion of new medications in the national treatment guidelines. Moreover, victories in the courts have helped to create specific legislation. Therefore, the consolidation of the rights of people living with HIV/AIDS has also had a consequential effect on the formulation of public policies.

Conclusions: Legal intervention to guarantee the rights of HIV-positive people, associated with a greater articulation of the social movement with other sectors, is the ideal path for the creation of efficient public policies on AIDS, which push the state to provide the services for which it is responsible.

Presented by Ingrid Carvalho, C Varela, B Maia, Grupo Pela VIDDA-RJ, Rio de Janeiro, RJ, Brazil.

**Abstract G1168:
Reviewing Programming
on HIV/AIDS, Human
Rights, and Development**

Issues: International legal obligations and sound public health practice require that policies and programs to reduce the spread and impact of HIV/AIDS respect human rights. In practice, difficulties arise in the design and delivery of rights-based HIV/AIDS programs. This is partly because some donors are still

considering what a rights-based approach means for HIV/AIDS programming. Similarly, human rights, democracy, and governance programs rarely include an HIV/AIDS perspective. The experience of rights-based programming on HIV/AIDS has not been adequately documented, yet the rights-based approach offers a potentially effective, globally integrated framework for addressing the underlying determinants of HIV infection, care, and impact over the longer term.

Description: In 2001, a government international development agency contracted an AIDS-law NGO with international experience to research these issues. The first phase of this project involves research into approaches by other bilateral donors and multilateral agencies – a roadmap of the work undertaken so far – and a statement of the rationale and legal basis for a rights-based approach to development programming in the context of HIV/AIDS.

Lessons learned: The project reviews the extent to which rights-based approaches have been incorporated into the HIV/AIDS programs of selected agencies, the experience in doing so, and how other rights-based programs have been adapted to respond to HIV/AIDS.

Recommendations: Donors, international development agencies, and national partners should review the experience with rights-based approaches to HIV programming at all levels. Programming tools based on this experience can then be developed to implement successful approaches.

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Abstract G8253: Bill of Rights of HIV-Positive Persons in Puerto Rico: Implications for the Public Policy Process

Issues: Despite prevention efforts, incidence rates of HIV and AIDS have increased. Unfortunately, state and society have reacted to the epidemic with many prejudices. As a result, HIV/AIDS patients have been treated unfairly. In most countries, their human rights have not been protected by the state. In Puerto Rico, the most significant public policy that has been adopted is the Bill of Rights of HIV-Positive Persons. It guarantees the right to intimacy, and to access to adequate services, and is thus one of the most important legal accomplishments in Latin America.

Description: The goals of this study were to analyze this bill by describing its goals and content; to examine issues surrounding its implementation; and to present recommendations for the formulation of similar policies. We interviewed legislators, directors, and employees of government agencies who work with HIV/AIDS. We also reviewed documents related to the bill.

Lessons learned: From our examination of the bill, we found that the state took an active role in designing a policy that guarantees social well-being and that it has also promoted social justice by seeking fair treatment for a population that is stigmatized and discriminated against. However, it should be noted that the policy does not protect the confidentiality of convicted sexual aggressors. From the interview process, we discovered that this bill contradicts other laws; that a budget was not assigned for its implementation, that the bill was not implemented due to

poor communication between agencies and legislators, and that most of the people interviewed lacked knowledge of the contents of the bill.

Recommendations: (a) Legislators should examine the policies they propose. (b) A communications structure should be designed for the people involved in public policy development. (c) A budget should be assigned to implement the bill. (d) The knowledge about the bill that HIV-positive patients and services providers have should be assessed. Despite its limitations, the bill represents an important step in public policy development that other countries should imitate.

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Abstract D4940: Effective Approaches to HIV/AIDS Prevention and the Protection of Rights of HIV-Positive Prison Inmates in the Russian Federation

Issues: In 2001, Russia's vast penal system experienced a 10- to 40-fold increase in new cases of HIV infection. The first reaction of the Ministry of Justice was to immediately isolate all HIV-positive inmates. Leading Russian HIV/AIDS experts championed this decision as being the most logical and the most beneficial for HIV-positive inmates. However, such decisions have further promoted discrimination and repeated breaches in the human rights of incarcerated individuals. AIDS Infoshare, in partnership with the Mojzhaisk prison colony, have developed a comprehensive program that targets prison administration, medical

and security personnel, and inmate populations. The program examines complex social, medical, behavioural, and legal aspects of HIV/AIDS, and identifies solutions tailored to Russia's prison context. The Mojzhaisk colony has demonstrated leadership in integrating HIV-positive inmates within the general prison population.

Description: Project research among inmates and prison staff examined levels of HIV/AIDS knowledge; prevalent behaviours among inmates (HIV-positive and HIV-negative); and attitudes toward HIV and HIV-positive people within the prison compound. The results shaped program methodologies. The participation of HIV-positive people was critical to the development and implementation of activities. Attitudes were monitored among all groups throughout the course of the project. Advantages and disadvantages of integration versus isolation of HIV-positive prisoners were examined.

Lessons learned: There are three key strategies to maximize program efficacy: (a) an integrated prison setting; (b) involvement of HIV-positive inmates in the development, implementation, and evaluation of activities; and (c) a complex approach targeting inmates and their immediate groups of influence, thereby reducing discrimination while safeguarding against human rights violations due to HIV status.

Recommendations: Developed program methodologies should be promoted to the Ministries of Justice in Russia and the newly independent states.

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