CANADIAN
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NEWSLETTER

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Supreme Court Rules in *R* v *Cuerrier*

In a judgment released on 3 September 1998 in the case of *R* v *Cuerrier*,[1] the Supreme Court of Canada unanimously decided that an HIV-positive person may be guilty of the crime of "assault" if they do not disclose their HIV-positive status before engaging in unprotected sexual activity. This article provides a history of the case, a summary of the Supreme Court's decision, and explains what the decision means for HIV-positive people in Canada.

Trial and appellate courts in Canada and other countries (including the US, the UK, Australia, Switzerland, Finland, and France) have previously decided cases where HIV-positive persons have been charged under criminal or public health laws for conduct that transmits or risks transmitting HIV.[2] However, this is the first time the highest court of any country has addressed the question of criminalizing risky activity by an HIV-positive person, and the Supreme Court's decision received considerable media attention and commentary.

Numerous individuals and organizations have expressed concerns, both before and since the decision in *Cuerrier,* about criminalizing non-disclosure of HIV-positive status.[3] The decision raises several questions for people with HIV/AIDS about disclosure in the context of sexual activity,

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

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UNAIDS

Legal, Ethical, and Human Rights Issues at Geneva98

At the 12th World AIDS Conference in Geneva in June/July 1998, many sessions were dedicated to legal, ethical, and human rights issues raised by HIV/AIDS, both in the scientific track of the Conference and in the Community Rendez-Vous section. In addition, a satellite meeting on AIDS and Human Rights organized by the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the International Council of AIDS Service Organizations (ICASO), and other activities throughout the conference allowed representatives from AIDS service organizations and from human rights organizations to meet each other and to learn from each other. In this special edition of the *Newsletter*, with funding from UNAIDS, we reproduce nine of the most relevant presentations on legal, ethical, and human rights issues given at the Conference – a must-read for all those in governments, the United Nations system, professional associations, and non-governmental and community-based organizations who are interested in the broader legal, ethical, and human rights implications of HIV/AIDS.

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Comments?

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

CANADIAN HIV/AIDS POLICY & LAW NEWSLETTER

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

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

Canadian HIV/AIDS Policy & Law Newsletter
Canadian HIV/AIDS Legal Network
484 McGill Street, 4th Floor
Montréal, QC H2Y 2H2
Tel: (514) 397-6828
Fax: (514) 397-8570
Email: enolet@aidslaw.ca

Editor: Ralf Jürgens
Copyeditors: Garry Bowers, David Garmaise, Jean Dussault
Translators: Garry Bowers, Roger Caron, Jean Dussault, Josée Dussault, Johanne Forget, Maryse Gagnon
Design and Layout: Communication Works, Ottawa

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CANADIAN HIV/AIDS LEGAL NETWORK
The Network is a charitable organization that educates about and promotes policy and legal responses to HIV infection and AIDS that respect human rights. It facilitates access to accurate and up-to-date legal information. It links people working with or concerned by relevant social and legal issues in order to limit the spread of HIV and to reduce the impact on those affected by HIV infection and AIDS. The Network is based in Montréal. We welcome new members. For membership information, contact Anne Renaud at <arenaud@aidslaw.ca>.

EDITORIAL

As you will have noticed, this is a special issue of the Newsletter. First, because, thanks to co-funding received from the Joint United Nations Programme on HIV/AIDS (UNAIDS), we have been able to include some of the most relevant presentations on legal, ethical, and human rights issues raised by HIV/AIDS given at the Geneva98 World AIDS Conference. As a result, this is the first truly international issue of the Newsletter, an issue that will be distributed worldwide to over 500 people and organizations with an interest in HIV/AIDS and human rights, particularly in developing countries, and that will be available through the Canadian HIV/AIDS Clearinghouse and on the Legal Network's website at <www.aidslaw.ca>. Second, because the Newsletter has a new look that, we believe, makes it more attractive. Third, because we have included new columns that will become regular features of the Newsletter, such as "HIV/AIDS in Canadian Courts." In this column, we will regularly provide a much more systematic review of Canadian court cases relating to HIV/AIDS than we were able to provide in the past. Another new feature is the in-depth review of new developments in criminal law and HIV/AIDS, in Canada and internationally. The next issue of the Newsletter will include such an in-depth review of new developments in another area that has traditionally been of interest to our readers: prisons. Finally, and probably most important, after this special issue we will go back to a quarterly publication schedule and provide regular updates on the important legal, ethical, and human rights issues raised by HIV/AIDS in Canada and internationally. To make the Newsletter more accessible, we will make it available on the Network's website shortly after publication.

The new Canadian Strategy on HIV/AIDS contains, for the first time, a component on legal, ethical, and human rights issues. This represents a huge step forward and a recognition that these issues must be an integral part of any strategy to fight HIV.

In Canada, the new Canadian Strategy on HIV/AIDS contains, for the first time, a component on legal, ethical, and human rights issues. This represents a huge step forward and a recognition that these issues must be an integral part of any strategy to fight HIV, for three reasons: because work aimed at ensuring that laws and policies facilitate rather than hinder efforts to prevent HIV/AIDS must be supported; because work aimed at ensuring that laws and policies facilitate rather than hinder efforts to provide care, treatment and support to people with HIV/AIDS must be supported; and because work aimed at ensuring that laws and policies respect and protect the rights of people with HIV/AIDS and those affected by the disease must be supported. A consultation on legal, ethical, and human rights issues raised by HIV/AIDS, undertaken by an independent consultant for the Legal Network and Health Canada, has shown that there is tremendous support for the new component of the Strategy, and has provided a plan that will guide action on legal, ethical, and human rights issues in the next five years.

Over the last years, Canada has taken a leadership role in the area of legal, ethical, and human rights issues raised by HIV/AIDS. The consultation processes leading to the production of authoritative documents on often controversial issues have come to be seen as best practice, and papers such as HIV Testing and Pregnancy: Medical and Legal Parameters of the Policy Debate, summarized in this issue, will be extremely useful to policymakers worldwide. Readers from outside Canada will thus find interesting not only the articles in the special, UNAIDS-funded section of this Newsletter, but also the articles on "Canadian" issues.

> Over the last years, Canada has taken a leadership role in the area of legal, ethical, and human rights issues raised by HIV/AIDS.

Canadian readers will in turn learn a lot from the international articles in this issue. It is not a coincidence that the second new component in the new Canadian Strategy on HIV/AIDS is the international component – for the first time, the Strategy contains an international focus with dedicated funding, evidence of the fact that Canadians are increasingly aware of, and interested in, the international dimension of the epidemic. But far beyond that, there are concrete lessons for Canada to be learned from the international articles. For example, the article by Justice Cameron points out how the lack of progress in responding to HIV/AIDS in many countries is largely due to the fact that these countries lack an effective and assertive activist community. In Canada, much of the progress achieved in the past was indeed due to the efforts of an effective and assertive activist community, mainly composed of people with HIV/AIDS whose voices were so loud and convincing that they could not be neglected. Without that community, there would likely not have been a new Strategy on HIV/AIDS, and prevention and care efforts would have been slower and less effective. However, in recent years, HIV/AIDS in Canada has increasingly affected even more marginalized populations – in particular, injection drug users, Aboriginal people, prisoners, and young gay men – who do not have effective and assertive activist communities. Little progress has been made to fight the epidemic in these populations. Indeed, as pointed out by Jan Skirrow in his article in this issue, a public health tragedy is underway among injection drug users, but few seem to care, and certainly there is an absence of political will to act to implement those measures that would make a difference. There seems to be more fear of being seen as condoning the use of drugs than of being seen as condoning the preventable spread of infection, resulting in the death of thousands. Another example is the epidemic of HIV that, as many have predicted for years, will severely affect Aboriginal populations in Canada. While all the efforts currently underway to curb the spread of HIV among Aboriginal populations are important, and while progress is indeed being made, efforts will be much less effective than they could be unless governments across Canada and the Aboriginal leadership take up HIV/AIDS among Aboriginal people as a major issue, and unless an assertive community of activists speaks out and forces action. In Canada, as worldwide, more than before, we need the passion, the anger, the enthusiasm, and the support of activist communities.

CANADIAN NEWS

Legal, Ethical, and Human Rights Issues Raised by HIV/AIDS: A Plan for 1999-2003

In the spring of 1998, Health Canada asked the Canadian HIV/AIDS Legal Network to lead a national planning exercise with the goal of developing a plan to address legal, ethical, and human rights issues associated with HIV/AIDS that may arise during the course of the Canadian Strategy on HIV/AIDS (CSHA) through 2003. Meetings with over 200 individuals and organizations were held between June 1998 and November 1998. In January 1999 the planning exercise came to a conclusion with the release of a planning report that contains 34 recommendations, providing a basis for immediate action.[1] This article by Brian Bell, an independent consultant who conducted the planning exercise and wrote the planning report, summarizes the main issues raised in the report.

Background

The Report is the product of a national planning exercise whose goal was to develop a plan to address priorities with regard to the legal, ethical, and human rights issues associated with HIV/AIDS that may arise during the course of the Canadian Strategy on HIV/AIDS (CSHA) through 2003.

Past work in the area of legal, ethical, and human rights issues related to HIV/AIDS has resulted in calls for, among other things, better HIV/AIDS prevention, care, and treatment in prisons, changes in laws and policies regarding drug use and the treatment of addictions, and changes to the laws and policies that discriminate against gay men, lesbians, bisexuals, and transgendered people. Such work has also supported interventions in key cases before the courts, contributed to policy changes made by federal, provincial, and territorial governments, and assisted lawyers and HIV/AIDS organizations in the advice and support they provide to individuals.

Consultations held in 1997 at the end of Phase II of the National AIDS Strategy confirmed the need for continuing efforts in this area, and the importance of this work was recognized in the new Canadian Strategy on HIV/AIDS announced by the Minister of Health in May 1998. Legal, ethical, and human rights issues were designated a strategic area and allocated $700,000 in annual funding.

The Legal Network was approached by Health Canada to lead this planning exercise, in recognition of the central role it has played in contributing to past efforts concerning legal, ethical, and human rights issues associated with HIV/AIDS in Canada.

People felt that a new component on legal, ethical, and human rights issues associted with HIV/AIDS was an important addition to the Strategy.

Considerable effort was made by both parties to ensure that people's input with regard to the planning was not prejudiced in any way by the Network's leadership role. This included ongoing dialogue with Health Canada in planning and conducting the meetings and hiring an independent consultant to facilitate the meetings and write the final report.

Objectives of the Plan

The objectives of the planning exercise were:

- to identify those legal, ethical, and human rights issues that require attention under the CSHA;
- to suggest how these issues might be addressed;
- to consider factors that could assist in determining what issues should be addressed first;
- to identify existing or potential organizations, partnerships, or networks that could be used or

developed to undertake activities;
- to suggest how funds should be allocated for these activities.

Developing the Plan

The Planning Process

The process for developing the plan was as follows:

- meetings were arranged with selected individuals and organizations across Canada in July, September, and October 1998 to obtain their views and some sense of the context of future work on legal, ethical, and human rights issues related to HIV/AIDS;
- participants included people with HIV/AIDS; populations affected by HIV/AIDS; AIDS service organizations; national and international non-governmental organizations; lawyers and staff of legal clinics, human rights commissions and organizations; experts in research, ethics and law, addiction/substance use; professional associations; health and public health practitioners; and government officials;
- a Discussion Paper was developed to provide background on legal, ethical, and human rights issues associated with HIV/AIDS, to guide discussion in the meetings and to provide a framework for organizing feedback. Eight questions invited input on issues, activities, roles and responsibilities, and how the funding should be used;
- participants were provided with a copy of the Discussion Paper prior to each meeting. The Paper was also posted on the Legal Network's website, with an invitation to all interested individuals and organizations to provide their comments. In addition, three meetings were scheduled around annual general meetings of national and provincial HIV/AIDS organizations to increase accessibility of the process to many harder-to-reach individuals;
- the meetings were facilitated by the Consultant, using the questions as a guide; more than seventy meetings were convened, with over 200 individuals associated with 60 organizations, in Halifax, Fredericton, Montréal, Ottawa, Toronto, Calgary, Edmonton, and Vancouver. In addition, several telephone interviews were arranged with individuals who were outside these centres and 26 people provided written comments;
- following the meetings, the Consultant prepared a draft planning paper, which was distributed to all the participants, and a national meeting was convened with 28 of the participants to review the draft planning paper in detail. The feedback from that meeting, together with other comments, were used to develop the final version of the plan; that draft was sent to all participants at the national meeting for further comment, to ensure that every participant felt that the discussion had been well captured in the plan. The plan was finalized, incorporating the additional comments.

People expressed a high degree of support for this planning process, and suggested that a similar kind of planning exercise needs to be undertaken in the other major components of the Strategy.

Feedback and Methodology

Feedback from the meetings and about the planning process was very positive. Eighty-four percent of respondents to an evaluation of the planning process stated that the sessions met their expectations, and over 90 percent assessed the effectiveness of the preparations, process, and content as high. Respondents described the meetings as inclusive, respectful, focused but flexible, and very important. In fact, the only major drawback appears to have been the lack of additional time for information sharing.

All the conclusions in the Report are based on the input received from participants in the meetings and are supported by a general consensus. In many cases, the vast majority of people agreed on a particular issue. In some cases, however, people expressed opposing viewpoints. In these instances, the conclusions reflect the broader view. Where it was felt, after the country-wide meetings, that certain questions still remained open or further clarity on particular issues was desirable, this was explicitly raised at the national meeting with a view to establishing some general agreement.

Situating Legal, Ethical, and Human Rights Issues Associated with HIV/AIDS

The meetings confirmed a very high degree of support for the introduction of a legal, ethical, and human rights component into the 1998 CSHA. People also felt very strongly that the planning process used for this component should be used as a model for other components of the Strategy.

There was a perception that there is still a need to promote better public awareness and understanding of both the human rights and ethical dimensions of the component. For example, Canadians are only beginning to appreciate the importance of a rights-based approach to HIV/AIDS as a way to ensure an effective and comprehensive response to the epidemic.

Priority Legal, Ethical and Human Rights Issues	
Most frequently mentioned (ie, almost all people mentioned and attached high priority to these issues)	• Care and treatment • Prisons • Testing
(a vast majority of people mentioned and attached high priority to these issues)	• Criminal law and HIV/AIDS • Drug laws, policies and programs
(a majority of people mentioned and attached high priority to these issues)	• Return to work • Poverty, income support, benefits, etc
(some people mentioned and attached high priority to these issues)	• Discrimination • Public health laws, policies and programs • Women's issues
(some people mentioned and attached high priority to these issues)	• Aboriginal issues • Children and youth issues • Gay and lesbian issues • Immigration and travel • Insurance • Legal services • Litigation, court challenges • Prostitution • Changing demographics • Development issues • Euthanasia • Health care and reform
Least frequently mentioned (ie, very few people mentioned and attached high priority to this issue)	• Estate planning

Desirable Features of a Plan

Feedback from participants suggested that for a plan to be effective it must speak to a number of general points that cut across all HIV/AIDS efforts. Chief among these points are:

- *The changing HIV/AIDS populations*: The realities of the HIV/AIDS epidemic, along with current care and treatment capacities, suggest the emergence of two quite distinct populations of people infected and affected by HIV/AIDS. One group includes those who are able to benefit from antiretroviral drugs and new combination therapies. For these people, issues such as income protection, insurance, and return to work are front and centre. The other group consists of the growing number of infected and affected people who are even more vulnerable and marginalized than the first group and for whom access to basic care, treatment, and rudimentary support remains an even greater life-and-death challenge. This group includes injection drug users, sex trade workers, transgendered people, many Aboriginal people and, to varying degrees, young gay men and others. Plans must recognize and speak concurrently to these two populations.
- *Flexibility and change*: Like the CSHA itself, the plan must be flexible and able to respond to continuous change in the epidemic itself; in technology and its impact on policy and practice associated with new efforts in prevention, care and treatment, testing and surveillance, tracking and reporting; and in organizational capacity.
- *Redefined "partnerships"*: The new CSHA commits to "new approaches and mechanisms [that] will be put in place to consolidate and coordinate sustained national action in the long term."[2] For this to happen, all players – both governments and non-government organizations – will be called on to make significant shifts in how they "do business."
- *Comprehensiveness and long-term commitment*: Planning must be comprehensive and strategies have to be conceived in a way that supports actions ranging from the initial investigation and research required to "scope" issues, to the appropriate follow-through, including communication and public education, advocacy, litigation, and institutional change.
- *Monitoring and accountability*: There is a need to develop the commitment and the tools to monitor progress on issues regardless of whether cast in the form of changes in laws, institution of new practices and guidelines, shifts in public awareness and changes in behaviours, or other options.

Conclusions

The report contains 34 conclusions. Among them are the following:

- the goal of legal, ethical, and human rights activities must be to ensure that laws, policies and programs respect and promote the rights of people with HIV/AIDS and contribute to the overall goals of the CSHA; promote and facili-

tate rather than hinder prevention efforts; and promote and facilitate rather than hinder efforts to provide care, support and treatment to people with HIV/AIDS;
- it is important to ensure that activities promote the rights of all people with HIV/AIDS: both those who are able to benefit from improved health associated with advanced care and treatments and those who cannot and who are more vulnerable and marginalized by social, economic, and other factors;
- people with HIV/AIDS and those affected must be included in activities undertaken in this area of the Strategy, and particular attention must be given to those who are marginalized and most vulnerable;
- legal, ethical, and human rights issues associated with HIV/AIDS can be prioritized for planning purposes within any year according to work that needs to be continued, work that is needed on previously unforeseen but now pressing issues, action on a new or outstanding issue, and pioneering work on a potentially critical issue for the future. However, this framework has to be seen as a dynamic process needing annual assessment and validation and periodic adjustment;
- there is a need to continue current activities associated with high-priority issues (eg, drug laws, return to work, discrimination, prisons, the decision in *R* v *Cuerrier,* and new testing technologies); certain activities need to be strengthened (eg, knowledge/communications regarding work that has been done on legal, ethical, and human rights issues); and additional activities are required – particularly in relation to improved legal services for people with HIV/AIDS and to strengthened local advocacy for legal, ethical, and human rights both for people with HIV/AIDS, and for improved legal, policy and program action;
- to effect progress on issues within this component (and across the Strategy generally), organizations have to develop ways to work together more effectively within an environment of mutual respect, transparency and accountability, to strengthen skills and resources that enable them to do so, and to reduce structural barriers to increased cooperation. This includes the need to strengthen and open up government intra- and interdepartmental coordinating and collaborative mechanisms;
- it is also important to strengthen links among federal departments, and with provincial/territorial governments, through existing committee structures to promote a good understanding of the goal of this component, and to strengthen funding support for the plan and required activities from within relevant funding sources;
- $700,000 for legal, ethical, and human rights issues raised by HIV/AIDS is not enough to adequately support all the activities that are required in this component, and further efforts are necessary to secure additional funding, particularly outside the Strategy;
- the Legal Network must continue to be supported through both sustained operational support and enriched, multi-year project support, so that it may continue to play the major leadership role expected of it within this component and continue work on high-priority current and emerging issues. The necessary funding arrangements must be in place quickly to allow the Network to continue its activities beyond 1 April 1999 without interruption; and
- a new mechanism to guide the allocation of project funding in the legal, ethical, and human rights component and to promote more integrated and effective planning is urgently required. This must include a peer review process and must be put into place prior to 1 April 1999.

The goal of legal, ethical, and human rights activities must be to ensure that laws, policies and programs respect and promote the rights of people with HIV/AIDS; promote and facilitate rather than hinder prevention efforts; and promote and facilitate rather than hinder efforts to provide care, support and treatment to people with HIV/AIDS.

The plan provides a basis for immediate action, with a view to contributing to strengthened, more focused and effective operations on legal, ethical, and human rights issues associated with HIV/AIDS beginning by 1 April 1999.

– Brian Bell

Brian Bell is a consultant with The Alder Group in Ottawa. He can be reached at <bbell@web.net>.

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[1] B Bell. *Legal, Ethical and Human Rights Issues Raised by HIV/AIDS: Where Do We Go from Here? Planning for 1998-2003. A Planning Report.* Montréal: Canadian HIV/AIDS Legal Network, 1999.

[2] *The Canadian Strategy on HIV/AIDS, Moving Forward Together.* Ottawa: Health Canada, May 1998.

HIV/AIDS IN CANADIAN COURTS

HIV/AIDS in Canadian Courts in 1998: An Overview

This column presents a summary of miscellaneous Canadian court cases in 1998 relating to HIV/AIDS. We will include such a review of cases as a regular feature in future issues of the *Newsletter.* A search of Canadian electronic legal databases yielded numerous cases reported in 1998 in which reference was made to HIV/AIDS. However, only those cases that dealt with HIV/AIDS in any substantive way have been summarized here; cases dealing with minor procedural matters related to litigation have been excluded. (Readers aware of any unreported cases that would be of interest to the Network and *Newsletter* readers are asked to draw these to the Network's attention.) The cases below deal with access to medical marijuana, immigration law, defamation, patent disputes over AZT, and tort litigation against the government and the Red Cross for HIV infection through tainted blood or blood products. Criminal cases are summarized elsewhere in this issue.

HIV-Positive Man's Constitutional Claim to Medical Marijuana Dismissed

In August 1998, the Ontario Court (General Division) dismissed an application brought by Jim Wakeford, an HIV-positive Toronto man, for a constitutional exemption from the provisions of the *Controlled Drugs and Substances Act*[1] (CDSA) so as to permit him to lawfully possess and cultivate marijuana for medicinal purposes, and for an order that the federal government provide him with a secure supply of marijuana for such purposes. In *Wakeford* v *Canada*,[2] the applicant argued that the prohibition violates his rights under s 7 of the *Canadian Charter of Rights and Freedoms* to "life, liberty and security of the person" and his right not be deprived of these guarantees "except in accordance with the principles of fundamental justice." The applicant argued that it does not accord with these principles to criminalize a person suffering from a serious chronic medical disability for possessing a vitally helpful substance not legally available to him in Canada. He further argued that the prohibition violates his s 15 Charter equality rights by discriminating against him (and others) on the basis of disability.

Evidence adduced before the Court indicated that Wakeford's physician had prescribed Marinol, a drug containing synthetic THC (the active ingredient in *cannabis sativa*) for the debilitating side effects (including nausea and loss of appetite) caused by medications prescribed for HIV disease. However, Marinol exacerbated Wakeford's ill health, and he began using marijuana under a physician's supervision. He discovered that, in addition to controlling his nausea and stimulating appetite, marijuana use also countered other side effects caused by his medications.

Possible ministerial exemption excuses law's infringement of Charter rights

Mr Justice LaForme ruled that, while the CDSA did not infringe Wakeford's right to "life," it did infringe his rights to "liberty" and to "security of the person." The Court accepted that the state's interest in criminalizing marijuana includes "preventing the harms associated with cannabis use; controlling the domestic and international trade in illicit drugs; and satisfying Canada's international treaty obligations with respect to the control of illicit drugs." He noted, however, court findings in the earlier case of *R* v *Clay*[3] that there is no evidence that cannabis consumption is addictive or causally connected to criminality, "hard drug" use, or psychosis. Furthermore, the court in *Clay* found that consumption of marijuana is relatively harmless compared with so-called hard drugs, tobacco, and alcohol, and that the health-related costs are negligible in comparison with tobacco and alcohol consumption.

LaForme J then considered whether this infringement of Wakeford's liberty and of the security of his person were in accordance with the "principles of fundamental justice." He noted that s 56 of the statute provides that the Minister of Health may exempt any person or any controlled substance from the application of the statute "if, in the opinion of the Minister, the exemption is necessary for a medical or scientific purpose or is otherwise in the public interest."

LaForme J therefore concluded that "if there is no real process or procedure whereby an individual in the situation of Mr Wakeford could seek to be exempt from the application of the CDSA, that would be contrary to the principles of fundamental justice. If that were the case I would have no hesitation in granting, perhaps even all, the relief Mr Wakeford seeks. However, Parliament has provided a specific means for individuals to apply for exemptions and that must be exhausted prior to this court's intervention. Mr Wakeford, I find, has not done so and, at this time, I am unable to hold that his denial of rights under s 7 of the Charter is not in accordance with the principles of fundamental justice."

However, LaForme J also added a warning to Parliament: "It should be obvious by now that our society must begin to seriously give consideration to the medical benefits of marijuana. Medical evidence and opinion, albeit not complete, clearly indicate that the time has come to examine this sincerely. ... [T]hese concerns [about the availability of 'clean' and affordable marijuana] are, in my view, valid and ought to be dealt with by Parliament if it has not done so or is not doing so. If such is not the case, the courts of this land will, without question, continue to be called upon and expected to provide a remedy for this very pressing and fundamentally important issue."

Equality rights argument dismissed

The Court also rejected Wakeford's claim that the CDSA discriminates against him on the basis of his disability (HIV), contrary to the equality rights guarantee in s 15 of the Charter. LaForme J affirmed that "individuals suffering from AIDS are included in the enumerated ground of physical disability" and "face ongoing discrimination in subtle and not so subtle ways." However, he took the view that the state was not discriminating against Wakeford or other HIV-positive people because: the statute does not deny to Wakeford medications that are available to other people; it is Wakeford's "choice" to smoke marijuana to treat his symptoms, rather than to use other, legal prescription drugs; and the ministerial exemption available under s 56 is a reasonable accommodation. LaForme J concluded that "no individuals are granted the right by legislation to virtually any and all drugs of their choice. The legislative scheme provides that any individual who desires controlled substances must obtain them in accordance with the regulations. The legislation does not deny Mr Wakeford the medication that he requires, it only in effect denies him the one medication he desires."

New developments

On 3 March 1999, the Minister of Health announced that the federal government would proceed with clinical trials of the medical use of marijuana. However, the issue of ensuring access to persons with HIV/AIDS and others in the interim, through the possible use of a Ministerial exemption, remains unaddressed.

Petition against Deportation Order by Father of HIV-Positive Child Dismissed

On 24 April 1998 the BC Supreme Court dismissed a petition brought on behalf of two Canadian-born children, by their father and litigation guardian, to stay his deportation by the Minister of Citizenship and Immigration.[4] The petitioning children and father argued that, pursuant to its *parens patriae* jurisdiction, the Court should prevent immigration officials from deporting the father until the children reached the age of majority. The elder of the children (two years old) is HIV-positive, and evidence before the Court indicated the children's mother was incapable of providing for their care.

Following an earlier decision of the same court raising similar issues (subsequently approved on appeal),[5] Kirkpatrick J said: "There can be little question that the circumstances of this case, especially C [the HIV-positive child], are difficult and engender enormous sympathy. However, those are the very compassionate and humanitarian considerations upon which the Minister may exempt a person from deportation under s. 114(2) of the Immigration Act." Given that there existed a "comprehensive statutory scheme of review in immigration matters" wherein the best interests of the children could be considered before the execution of a deportation order, the Court ruled that its *parens patriae* jurisdiction does not extend to prevent immigration authorities from executing a removal order of a parent of Canadian-born infant children.

Defamatory Allegation of Not Disclosing HIV-Positive Status to Spouse

On 15 April 1998, in *Southam Inc* v *Chelekis*,[6] the BC Supreme Court awarded $50,000 in general damages to a *Vancouver Sun* columnist for slander by a rival journalist to the effect that the columnist had not informed his wife of his alleged HIV-positive status. The slanderous statement was made in May 1995 to attendants at a seminar at a Vancouver conference of investors, and was but one in a prolonged campaign by the defendant to defame and harass the plaintiff. Numerous other deliberately false publications about the plaintiff accused him of threatening the defendant's secretary and of fraudulent criminal activity regarding the Vancouver stock market. The Court awarded $525,000 in general damages with respect to the other libelous publications. For the entirety of the defendant's malicious and outrageous campaign against the plaintiff, the Court awarded $100,000 in aggravated damages as additional compensation for the damage to the plaintiff, and $100,000 in punitive damages to punish the defendant for his deliberate lies about the plaintiff.

Court Rules on Patent Dispute over AZT – Appeal Still Outstanding

In March 1998 the Federal Court (Trial Division) delivered its 161-page judgment in a patent dispute between Glaxo Wellcome Inc and generic drug manufacturers Apotex Inc and Novopharm Ltd over the drug commonly known as AZT (sold under the trade names zidovudine and retrovir).[7] In litigation commenced in 1990, Apotex and Novopharm sought a court declaration that Glaxo's patent (issued in June 1988) regarding pharmaceutical formulations containing AZT was invalid. Glaxo countersued Apotex in 1991, and then Novopharm in 1993, alleging patent infringement by selling AZT in Canada in dosage form.

Weston J of the Federal Court (Trial Division) ruled that Glaxo's patent was largely valid with respect to its claim of having invented the use of AZT in the treatment and prophylaxis of HIV, but ruled against Glaxo with respect to its patent claim for use of AZT as treatment or prophylaxis for *all* human retroviruses, finding that this was overbroad and exceeded the scope of Glaxo's invention.

Weston J rejected the argument by Apotex and Novopharm that Glaxo's "invention" was merely a method of medical treatment (which is not patentable under Canadian law); rather, he concluded that the subject matter of Glaxo's patent was the invention of a new therapeutic use for an already existing compound, noting that the patent claim "also exhibits commercial elements, ie, the new use is intended for the manufacture and sale of a pharmaceutical product, and is thus not simply to increase the efficacy of the day to day practice of physicians and other medical professionals."[8]

Weston J also found that Glaxo had satisfied the requirements of an "invention" as of 16 March 1985, and as such it could be patented. In February of that year, preliminary laboratory results had indicated to Glaxo scientists the possibility of AZT's utility in treating HIV infection. The Court held that this was insufficient to constitute an "invention" at this point, as it remained merely an idea. However, these results prompted Glaxo scientists to conduct a rapid series of pre-clinical studies of AZT in animals by mid March 1985, which suggested that human trials should proceed. The Federal Court therefore concluded that, by this point, Glaxo scientists "had more than a belief or idea that AZT would be useful as an experimental antiviral agent. It was more than abstract theory or scientific principle. At this stage, further inventive steps were no longer required but rather further testing, both in the laboratory and the clinic."[9] Accordingly, as of that date Glaxo had completed an "invention" within the meaning of the *Patent Act.*

In considering Glaxo's countersuit, Weston J found that the generic manufacturers had infringed the valid aspects of Glaxo's patent. He issued a permanent injunction prohibiting Apotex and Novopharm from importing, manufacturing, advertising, or selling AZT in pharmaceutical dosage form. He further ordered them to deliver up to Glaxo for destruction all AZT in their possession, custody, or control, and awarded Glaxo damages pursuant to the *Patent Act.*

On 24 July 1998 the Federal Court of Appeal stayed the trial judge's order until the appeal brought by Apotex and Novopharm could be heard, and ordered Glaxo to return the seized medicine.[10] In January 1999 the Supreme Court of Canada dismissed Glaxo's application for leave to appeal this order, without reasons.[11] The generic manufacturers' appeal of the ruling that they had infringed Glaxo's valid patent remains to be heard.

Plaintiff Not Required to Re-litigate Issue of Red Cross Negligence in Blood Screening

In October 1998 the Ontario Court (General Division) released a ruling assisting a plaintiff's lawsuit against a hospital and the Canadian Red Cross Society for his HIV infection as a child as a result of receiving tainted blood during heart surgery in 1985. In *Vos* v *Hospital for Sick Children*,[12] the plaintiff alleged the Red Cross was negligent in the screening of "high risk" blood donors and in failing to warn users of blood and blood products and their physicians of the dangers of HIV transmission through transfusion. The Red Cross denied any negligence. The plaintiff Vos sought a court ruling that findings already made by the courts in other lawsuits[13] that the Red Cross had been negligent in this regard should mean it is prevented ("estopped") from continuing to deny negligence. Benotto J agreed that to permit the Red Cross to re-litigate issues that it has already fully litigated and lost would amount to an abuse of the court's process, and that it would be "unconscionable to require the plaintiffs to reproduce the evidence and arguments" of the earlier cases regarding the Red Cross's failure to meet the proper standard of care.

More Blood Cases – Court Rules No Independent Lawsuit Permissible for Destroying Documents

In two judgments delivered in March and May 1998, Feldman J of the Ontario Court (General Division) granted permission to plaintiffs in three different lawsuits to amend their existing proceedings against hospitals, the Canadian Red Cross Society, and the Ontario government.[14] The plaintiffs alleged that Ontario was negligent in, among other things, not directing the Red Cross to destroy unheated blood product (particularly in light of its alleged "dominant position" on the Canadian Blood Committee). The plaintiffs further wished to pursue an additional claim against the Ontario government for *spoliation* (destruction of evidence). The plaintiffs alleged that Ontario sanctioned the Blood Committee's destruction of audio tapes and transcripts of the Committtee's meetings between 1982 and 1989, knowing that they contained material evidence about the transmission of HIV through blood products and the role of both the Ontario government and the Committee in this occurrence.

Although an unsettled claim in Canadian (and US) law, Feldman J followed Supreme Court of Canada jurisprudence[15] in letting the novel claim proceed for a final determination by a trial court. She also permitted the new allegation regarding the provincial government's negligence. However, Feldman J's decision was overturned on appeal by Ontario's Divisional Court in October 1998.[16] Citing the April 1998 decision of the BC Court of Appeal in *Endean* v *Canadian Red Cross Society*,[17] O'Driscoll J ruled that an independent cause of action for spoliation does not exist in Canadian law. Rather, the Court said that there existed merely an evidentiary rule that the Court would presume the destroyed evidence would have been damaging to the party who destroyed it.

Findings of Blood Inquiry Commissioner Not Admissible As Evidence in Civil Lawsuits

In December 1998, in the same three lawsuits against hospitals and the Red Cross, the Ontario Court (General Division) dismissed the plaintiffs' motion to have the report of the Royal Commission of Inquiry into the Blood System (the "Krever Report") and the report of the federal Information Commissioner (the "Grace Report") admitted into evidence as proof of the matters contained in those reports. The Court ruled that the findings in those reports were not intended to be used in subsequent civil lawsuits, and that in reaching their conclusions, the Commissioners had used evidence that would not be admissible in a civil proceeding.[18]

– Richard Elliott

Richard Elliott is Director, Policy & Research of the Canadian HIV/AIDS Legal Network. He can be reached at <relliott@netrover.com>.

The Editor would like to thank Ruth Carey and the HIV/AIDS Legal Clinic Ontario for providing the results of their preliminary research.

Québec Court of Appeal Rules on the Constitutionality of Law on Anal Sex

The Québec Court of Appeal, in a decision handed down on 15 April 1998, ruled section 159(2) of the *Criminal Code* unconstitutional. The section in question prohibits anal intercourse between unmarried persons if one of the partners is less than 18 years of age.

Roy[1] is not the first case in which the constitutionality of section 159 of the *Criminal Code* has been challenged. The Federal Court in *Halm* v *Canada*[2] and the Ontario Court of Appeal in *R* v *Carmen M*[3] both ruled section 159 unconstitutional and their reasoning was followed by the Québec Court of Appeal.[4]

The facts in *Roy* were that Henry Roy had oral and anal sex with GB, a 16-year-old male. The sex was consensual, so Roy was acquitted of charges of sexual assault; but the charge under section 159, having had anal intercourse with a minor, was maintained.

As his only means of defence, the accused raised the unconstitutionality of the *Criminal Code* provision, charging that it was discriminatory on the grounds of age, sexual orientation, and marital status, in breach of the *Canadian Charter of Rights and Freedoms*. This argument was rejected by the trial judge, who considered that Roy did not have the requisite standing to impugn the constitutionality of section 159 of the *Criminal Code* and that, furthermore, the provision in question infringed none of his rights. Roy was found guilty of anal intercourse with a minor.

On appeal, Roy argued that he had the requisite standing and he again raised the unconstitutionality of section 159; the Ontario Court of Appeal had recently held that the section was in fact unconstitutional. The prosecutor for the Attorney General of Québec then agreed to the quashing of the conviction and to Roy's being acquitted, provided that the Québec Court of Appeal agreed with the decision of its Ontario counterpart.

In his analysis, Justice LeBel first examined the definition and scope of the impugned provision of the *Criminal Code*. According to him, it was an attempt to modernize the "old crime of sodomy," a term that had been dropped in favour of "anal intercourse." Despite terminological progress, however, the section still prohibits such consensual sexual relations except where they are engaged in, in private, between any two persons, both of whom are more than 18 years of age or, if one of the partners is between 14 and 18 years of age, where the two persons are married.

LeBel JA then stated that the trial judge had erred in law in his decision to the effect that Mr Roy did not have the requisite standing to contest the constitutionality of a provision of the *Criminal Code*. The trial judge held that Roy would first have to prove that he was gay and that he

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[1] SC 1996, c 19.

[2] [1998] OJ No 3522 (Ont Ct Gen Div) (QL).

[3] (1997), 9 CR (5th) 349 (Ont Ct Gen Div), [1997] OJ No 3333 (QL) (under appeal).

[4] *CK* v *Canada (Minister of Citizenship and Immigration)*, [1998] BCJ No 978 (SC) (QL).

[5] *Torres-Samuels (Guardian ad litem of)* v *Canada (Minister of Citizenship and Immigration)*, [1998] BCJ No 386 (SC) (QL), aff'd [1998] BCJ No 2473 (CA).

[6] [1998] BCJ No 848 (SC) (QL).

[7] *Apotex Inc* v *Wellcome Foundation Ltd* (1998), 145 FTR 161, 79 CPR (3d) 193; [1998] FCJ No 382 (TD) (QL).

[8] Ibid, para 74.

[9] *Apotex*, supra, note 7 at para 184.

[10] (1988), 232 NR 40; 82 CPR (3d) 429; [1998] FCJ No 1088 (Fed CA) (QL).

[11] [1998] SCCA No 489 (QL).

[12] [1998] OJ No 4369 (Gen Div) (QL).

[13] See *Walker Estate* v *York Finch General Hospital* (1997), 39 CCLT (2d) 1 (Ont Ct Gen Div).

[14] *Robb Estate* v *St Joseph's Health Centre*; *Rintoul* v *St Joseph's Health Centre*; *Farrow* v *Canadian Red Cross Society* (1998), 42 CCLT 215; [1998] OJ No 1144 (Gen Div) (QL) (18 March 1998); and unreported decision of 29 May 1998, Ont Ct (Gen Div), Toronto, Feldman J.

[15] *Hunt* v Carey (1990), 49 BCLR (2d) 273 (SCC).

[16] [1998] OJ No 4074 (Div Ct) (QL).

[17] [1998] BCJ No 724 (QL) (CA); leave to appeal to SCC granted 19 November 1998 (without reasons), SCC Bulletin 1998, at 1778, [1998] SCCA No 210.

[18] [1998] OJ No 5394.

belonged to a distinct and historically disadvantaged group, in order to claim that section 159 was discriminatory on the ground of sexual orientation. Since this argument had already been rejected by the Supreme Court of Canada,[5] LeBel JA followed the decision of the Ontario Court of Appeal, which had recognized that the appellant had the requisite standing to challenge the constitutionality of section 159 of the *Criminal Code*.

LeBel JA then strongly criticized the trial judge's refusal to recognize sexual orientation as a prohibited ground of discrimination within the meaning of section 15 of the Charter. In doing so, LeBel JA surveyed the relevant case law and concluded that sexual orientation is indeed an analogous ground of discrimination prohibited by the Charter. He pointed out that age and marital status are also grounds of discrimination prohibited under section 15(1) of the Charter.

On the question whether the distinctions created by section 159 of the *Criminal Code* were discriminatory and infringed the Charter, LeBel JA held, after analyzing in detail the Supreme Court jurisprudence on discrimination, that the impugned provision created distinctions based on sexual orientation, age, and marital status, which had the effect of limiting the sexual freedom of adolescents between the ages of 14 and 18, and more particularly that of young homosexuals.

LeBel JA held that section 159 imposes a greater burden on minors. Under the *Criminal Code*, adolescents aged 14 and over can consent to vaginal or oral intercourse, which is not the case for anal intercourse, and accordingly this constitutes a distinction based on age. Section 159 also includes a distinction based on marital status, since unmarried persons between 14 and 18 years of age may not engage in anal intercourse before the age of 18, whereas married persons may. Finally, section 159 creates a distinction based on sexual orientation, since it prevents homosexual minors from having their "usual," consensual and private sexual relations before the age of 18. LeBel JA added that such a distinction perpetuates the historical disadvantages suffered by homosexuals, in violation of the principles of liberty and human dignity.

LeBel JA then sought to determine whether the discriminatory distinctions established by section 159 were justified or not. Accordingly, he first applied the test established in *Oakes* respecting section 1 of the Charter. The *Oakes* test consists in determining whether measures found to be discriminatory can be justified in a free and democratic society. LeBel JA sought to identify the objective of Parliament when the provision was included in the *Criminal Code*, more precisely before the 1988 reform. He insisted that there must be a rational connection between the objective and the measures taken, and that there must be minimal impairment of any infringed rights, if such rights had to be infringed.

In the context of section 159, LeBel JA said that Parliament had two main objectives. The first was to dissuade young homosexuals from having "unusual" sexual relations and the second was to protect them against the risks, both physical and psychological, associated with anal intercourse, such as increased risk of HIV transmission. In both *Halm* v *Canada* and *R* v *Carmen M*, the Crown prosecutors had acknowledged the unconstitutionality of the first objective, which was unjustified in a free and democratic society. With regard to the second objective, LeBel JA considered that the intent of Parliament to protect youth against the risks involved in anal intercourse was well-founded, but that section 159 concerns all types of sexual relations. He concluded that the equality rights of young homosexuals were not minimally impaired, as required by *Oakes*, and that the infringement was not proportional to the objectives sought to be attained. Accordingly, he held that section 159 was a violation of section 15 of the Charter and could not be saved under section 1.

– Antoine Bédard

Antoine Bédard has a degree from the Faculty of Law of McGill University, where he currently works as a research assistant in the area of ethics and genetics. He does occasional research for the Canadian HIV/AIDS Legal Network. His email address is <jetboy2000@hotmail.com>.

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[1] *R* v *Roy* [1998] A.Q. no 935 (No 500-10-000304-947 (750-01-001862-901 C.Q.St-H.).

[2] *Halm* v *Canada (Minister of Employment and Immigration)*, [1995] FCJ no 303 (24 February 1995).

[3] *R* v *Carmen M* (1992), 75 CCC (3d) 556; 15 CR (4th) 368 (Ont Ct Gen Div); (1995), 98 CCC (3d) 481 (Ont Ct App).

4 Both decisions were summarized in D Patterson. Anal Sex Law Ruled Discriminatory. *Canadian HIV/AIDS Policy & Law Newsletter* 1995; 1(4): 3-4.

[5] See *R* v *Big M Drug Mart Ltd*, [1985] 1 SCR 295 at 313.

LEGAL CLINICS

The Montréal Legal Clinic for People with HIV/AIDS

This is the second in a series of articles about legal clinics that provide specialized services to people with HIV/AIDS. In the previous issue of the *Newsletter*, Ruth Carey provided an overview of the work of the HIV & AIDS Legal Clinic, Ontario (HALCO).[1] In this article, lawyer Johanne Leroux describes the work of the legal clinic of the Québec Committee for people with HIV in Montréal. The main concerns that emerge from its work are group insurance, disability insurance and eligibility criteria, keeping one's job or returning to work and, always in the background, the difficulties involved in keeping medical files and information confidential.

The Committee and Its Legal Clinic

Founded in 1987, the Comité des personnes atteintes du VIH du Québec [Québec Committee for people with HIV] (Committee) is a community organization whose goal is to defend and promote the rights of people with HIV/AIDS, with a view to improving their quality of life. For eight years, the Committee's legal clinic has provided its members and those close to them with legal information and advice. It also has a mission to represent the interests of people with HIV and to lobby government authorities on their behalf.

These services are provided by a lawyer and four articling students from the law faculties of the University of Montréal and McGill University. We also collaborate with lawyers who specialize in areas of the law most relevant to the problems of our clients. These lawyers are supported by our team in the preparation of their files, which enables us to monitor their cases, keep informed of court decisions, and identify situations favourable to the development of new case law concerning HIV.

The legal clinic also offers free legal workshops for organizations fighting against HIV/AIDS. The workshops are informal and take the form of roundtables, which encourage exchanges of views.

The Legal Clinic's Monitoring of Major-Issue Files

Since the implementation of the *Act respecting prescription drug insurance*, the legal clinic's team has been working to inform its members of their rights under the new drug-insurance plan. It has also called for certain shortcomings observed in the Act to be rectified, in particular to make the plan accessible to federal employees and to enable premiums to be made in instalments.

Group Insurance

In addition to the breaches of confidentiality raised in our organization's brief to the Commission de la culture with regard to mandatory membership in prescription drug insurance plans provided by employers through group insurance in the workplace, we have documented several new cases concerning difficulties encountered by people with HIV since the advent of the new combination therapies. For example, during pre-hiring: comprehensive questionnaires on health status and on use of prescription drugs, medical exam, blood and urine analyses. In the case of a change of insurance company during the course of employment: insurer's access to the medical file during the qualifying period; non-eligibility for life insurance; diffi-

Since the spring of 1998, the Québec Pension Board has been increasingly reluctant to grant disability pensions to people with HIV.

culties regarding eligibility for disability insurance because of pre-existing conditions. Furthermore, since the coming into force of mandatory prescription drug insurance, high employer costs lead in some instances to harassment in the workplace, to penalties, or to dismissal.

Disability Insurance

Insurance companies require that disabled policyholders file an application for a disability pension with the Québec Pension Board (QPB). Following a negative response from the QPB, insured persons are not permitted to continue to claim disability insurance benefits. The *immediate effects* are loss of disability insurance benefits, loss of employment, or stormy negotiations for a return to work.

Moreover, after a disability period of 18 to 24 months, insurance companies call the disability status of the beneficiary into question. The *consequences* are that after the insured submits a medical report, the insurance company requires a second opinion (and, with one exception, we have documented the subsequent decisions of the insurance companies as being the discontinuation of disability status and benefits).

Another concern is connected with the fact that if a recipient of disability insurance benefits refuses the combination therapies proposed by their doctor, the insurer will discontinue their benefits immediately and without notice.

Québec Pension Board

Since the spring of 1998, the Québec Pension Board has been increasingly reluctant to grant disability pensions to people with HIV. According to the QPB's definition, a person who cannot engage in their everyday activities may receive a disability pension. However, since the advent of combination therapies, the physical status of people with HIV is not the only criterion to consider: doctors are now advised to comment on the psychological state of the patient.

Income Security

The new policies of the Ministère de la Sécurité du revenu are reassuring for beneficiaries who are already part of the Financial Support program. Indeed, during the 48 months following a beneficiary's decision to try to return to the workplace, they may be readmitted to the program if their state of health deteriorates and they cannot continue their reintegration process. Moreover, it has been recommended that the eligibility criteria take into account the person's psychological state.

Return to Work

Since the fall of 1997, the return-to-work issue has become a ubiquitous issue for people with HIV. Whether willingly or because they are forced to do so because of decisions made by insurers or because of increasing poverty, many people find themselves having to consider returning to work or reorienting their career. There are many legal, physical, psychological, and economic issues to be considered, in particular: the screening test upon hiring; the obligation of employers to provide information about AIDS in the workplace under the *Act respecting occupational health and safety*; increased union awareness of the rights of people with HIV; assertion of the rights of people with HIV vis-à-vis various government departments (Income Security, Labour, Revenue, Health and Social Services, Justice).

The Legal Clinic's Activities

Drug Insurance

To continue to make representations to the Québec Health Insurance Board, private insurance companies, and the Ombudsman in order to obtain freedom of choice regarding membership in the Québec prescription drug insurance plan and in group insurance in the workplace.

Group Insurance

To advocate for the respect of the confidentiality of medical files of people with HIV/AIDS, and respect for their right to work and to continue working.

Disability Insurance

To maintain contacts with treating physicians in order to properly document side effects and progress in treatments. The personal day planner our organization gives to people with HIV/AIDS should remain a useful tool for documenting their daily regimen.

Québec Pension Board and Income Security

To maintain contact with and to advocate in favour of the rights of people with HIV/AIDS before the appropriate government authorities.

Continued from previous page.

Return to Work

To develop the legal clinic's excellence in the areas of return to work and job stabilization; assertion of rights provided by labour law; development of legal presumptions in favour of people with HIV/AIDS.

2nd Workshop on HIV/AIDS and the Law

For the second university workshop on HIV/AIDS and the law, the articling students were asked to address the following subjects: legal and ethical issues relating to refusal of treatment; human rights, definitions of handicap and chronic illness; drug dependency, right to treatment and HIV/AIDS; civil liability and transmission of HIV.

Individual Files

We respect the confidentiality of the individual files relating to the defence of the rights of people with HIV/AIDS. However, during the course of the coming year we intend to ask those concerned for authorization to make public certain decisions in order to encourage more people to file complaints and to assert their rights.

– Johanne Leroux

Johanne Leroux is a lawyer and coordinator of the legal clinic of the Committee for people with HIV. From Montréal and abroad, the legal clinic can be reached at (514) 521-8720; from other regions in Québec at 1-800-927-2844, a toll-free number; and by email at <juridique@arobas.net>.

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[1] R Carey. Provision of Legal Services to Persons with HIV or AIDS: Barriers and Trends. *Canadian HIV/AIDS Policy & Law Newsletter* 1997/98; 3(4)/4(1): 9-11.

Supreme Court Rules in *R* v *Cuerrier*

(cont'd from page 1)

but may also have ramifications in other areas. The Canadian HIV/AIDS Legal Network (Network) is currently undertaking a project on the implications of *Cuerrier*, to identify issues that require further follow-up.

Background

In August 1992, Cuerrier (HC) was told by a public health nurse that he was HIV-antibody positive, and that he should use condoms for sex and tell his sexual partners about his HIV-positive status. He said he could not disclose this in his small community. Soon after, he began a relationship with KM, including frequent unprotected vaginal sex. Within a week of first having sex, KM discussed sexually transmitted diseases (STDs) with HC. He told her of his recent sexual encounters with women who themselves had had numerous partners. KM did not specifically ask about HIV; HC told her he had tested HIV-negative several months earlier, but did not mention his recent positive test result. KM said at trial that she knew the risks of unprotected sex, including HIV and other STDs.

A few months later, both HC and KM had HIV-antibody tests. He tested HIV-positive; she tested HIV-negative. Both were told of HC's infection, and advised to use condoms for sex. KM was told she would need further tests because she might still test HIV-positive. HC said he did not want to use condoms, and that if KM still tested negative in a few months, he would look for a relationship with a woman who was already HIV-positive. They continued having unprotected sex for 15 months. KM later testified that: (1) she loved HC and did not want to lose him; (2) as they had already had unprotected sex, she felt she was probably already infected; (3) however, she would not have had sex with HC had she known his HIV status at the outset. At the time of trial, she tested HIV-negative.

> This is the first time the highest court of any country has addressed the question of criminalizing risky activity by an HIV-positive person.

A few months later, HC began a sexual relationship with BH. After their first sexual encounter, she told him she was afraid of diseases, but did not specifically mention HIV. HC did not tell her he was HIV-positive. No condom was used for about half of their 10 sexual encounters. BH then discovered that HC was HIV-positive and confronted him, at which point he said he was sorry and should have told her. BH was not infected.

The Charges and Proceedings in the Lower Courts

HC was charged with two counts of aggravated assault (not *sexual* assault). Section 265(1) of the *Criminal Code* provides: "A person commits an assault when ... without the consent of another person, he applies force intentionally to that other person, directly or indirectly."[4] Section 268 of the Code provides: "(1) Every one commits an *aggravated* assault who wounds, maims, disfigures or endangers the life of the complainant. (2) Every one who commits an aggravated assault is guilty of an indictable offence and liable to imprisonment for a term not exceeding fourteen years."[5]

The Crown argued that the consent of HC's two partners was not legally valid (that it was "vitiated") because they were unaware of his HIV-positive status. The chief argument was that HC's non-disclosure constituted "fraud," thus making the physical sexual contact an assault under the *Criminal Code*. In defining the offence of assault, s 265(3) of the Code states that: "For the purposes of this section, no consent [to physical contact] is obtained where the complainant submits or does not resist by reason of ... fraud."[6]

As in the earlier Ontario case of *R* v *Ssenyonga*,[7] the defence successfully moved before the trial judge for a directed verdict of acquittal, on the ground that the Crown had not established the necessary elements to prove the offence of assault because the complainants had consented to the sexual activity. The Crown appealed to the BC Court of Appeal. The BC Persons with AIDS Society (BCPWA) and the BC Civil Liberties Association (BCCLA) intervened to make submissions against the use of criminal sanctions in this case. The five appellate justices unanimously dismissed the Crown's appeal, the majority noting: "The criminal law of assault is, indeed, an unusual instrument for attempting to ensure safer sex."[8]

The Crown's further appeal to the Supreme Court of Canada was heard in March 1998. The Ontario Attorney General intervened to advance the arguments it had unsuccessfully presented in *Ssenyonga*. The BCCLA intervened again, and the Canadian AIDS Society (CAS) and the Network filed a joint intervention with BCPWA. These interveners opposed the use of the assault provisions of the *Criminal Code* to criminalize non-disclosure of HIV-positive status, arguing, among other things, that invoking the criminal law would likely do little good and might harm other, more effective efforts to prevent HIV transmission.

The Supreme Court of Canada: "Fraud" and the Duty to Disclose

The Supreme Court allowed the Crown's appeal, reversed the decisions of the two lower courts, and ordered the matter sent back for a new trial. The seven-justice panel unanimously concluded that HC's non-disclosure of his HIV-positive status could constitute a "fraud" vitiating his partners' consent to sex. While the entire panel found the law's existing approach to fraud in the context of sex and assault inadequate, it was strongly divided as to the appropriate analytical approach to be taken. Justice Cory wrote the Court's majority opinion (Major, Bastarache, and Binnie JJ concurring), while L'Heureux-Dube J and McLachlin J (Gonthier J concurring) each wrote separate minority opinions sharply at odds with both each other and that of the majority.

Traditional Approach to Defining "Fraud"

Traditionally at common law, only fraud as to the "nature and quality of the act" or the identity of the person accused of assault could vitiate the complainant's consent to engage in sexual activity. In the early UK case of *R* v *Clarence* (1888), 22 QBD 23, the court held that a husband's failure to disclose that he had gonorrhea did not vitiate his wife's consent to sexual intercourse.[9] This limited approach to defining fraud that vitiates consent to sex was subsequently applied for over a century in the Canadian, Australian, and UK jurisprudence, although US courts took a different view.[10]

Such an approach was also reflected in the Canadian *Criminal Code*. Until 1983, the Code's definitions of "rape"[11] and "indecent assault"[12] stated that a complainant's consent would not be a defence to these charges if it were "obtained by false and fraudulent representations as to the nature and quality of the act." (The general definition of "assault" referred simply to consent "obtained by fraud," with no qualifier.) In 1983, Parliament replaced the offences of rape and indecent assault with the offence of "sexual assault."[13] The new offence incorporates the general definition of assault, which states simply that there is no consent where the complainant submits or does not resist to the application of force because of "fraud"; there is no qualifier describing the fraud that will vitiate consent.[14] There is currently no express reference to "nature and quality of the act" in the Code's assault provisions.

The BC Court of Appeal, relying upon an earlier decision,[15] ruled in

"For the accused to conceal or fail to disclose that he is HIV-positive can constitute fraud which may vitiate consent to sexual intercourse...."

Cuerrier that these amendments to the Code did not oust the existing common law rule that the fraud must relate to the "nature and quality of the act" in order to vitiate consent.

A Harm-Based Approach to Fraud: The Majority Judgment

However, the majority of the Supreme Court rejected this limited definition of fraud. Citing the legislative history and the "plain language" of the Code, Cory J concluded:

> Parliament's intention was to provide a more flexible concept of fraud in assault and sexual assault cases.... I would therefore conclude that it is no longer necessary when examining whether consent in assault or sexual assault cases was vitiated by fraud to consider whether the fraud related to the nature and quality of the act. A principled approach consistent with the plain language of the section and an appropriate approach to consent in sexual assault matters is preferable. To that end, I see no reason why, with appropriate modifications, the principles which have historically been applied in relation to fraud in criminal law cannot be used.[16]

Citing earlier decisions of the UK House of Lords and the Supreme Court of Canada dealing with criminal fraud, Cory J identified the two necessary elements of "fraud" in the commercial context: (1) an act which a reasonable person would see as *dishonest*, and (2) *deprivation*, or a risk of deprivation, as a result of that dishonest act.[17]

Noting that "deliberate deceit" has always been recognized as fraudulent conduct, Cory J looked to recent Supreme Court jurisprudence in concluding that fraud could also encompass non-disclosure "in circumstances where it would be viewed by the reasonable person as dishonest.... This ... can include the non-disclosure of important facts."[18] Criticizing the language, reasoning, and conclusion in *Clarence* as reflecting a "harsh and antiquated view of marriage,"[19] Cory J ruled:

> The deadly consequences that non-disclosure of the risk of HIV infection can have on an unknowing victim, make it imperative that as a policy the broader view of fraud vitiating consent advocated in the pre-*Clarence* cases and in the U.S. decisions should be adopted. Neither can it be forgotten that the *Criminal Code* has been evolving to reflect society's attitude towards the true nature of the consent.... In my view, it should now be taken that for the accused to conceal or fail to disclose that he is HIV-positive can constitute fraud which may vitiate consent to sexual intercourse.... It would be pointless to speculate whether consent would more readily follow deliberate falsehoods than failure to disclose. The possible consequence of engaging in unprotected intercourse with an HIV-positive partner is death. In these circumstances there can be no basis for distinguishing between lies and a deliberate failure to disclose.[20]

Thus, the majority concludes that non-disclosure may be considered objectively dishonest. But this can only be the case if there is a duty to disclose. The majority first states, seemingly categorically, that disclosure is always required to obtain legally valid consent:

> Without disclosure of HIV status there cannot be a true consent. The consent cannot simply be to have sexual intercourse. Rather it must be consent to have intercourse with a partner who is HIV-positive. True consent cannot be given if there has not been a disclosure by the accused of his HIV-positive status. A consent that is not based upon knowledge of the significant relevant factors is not a valid consent.

Yet this assertion is subsequently qualified by the suggestion that, in fact, disclosure may not always be required:

> The extent of the duty to disclose will increase with the risks attendant upon the act of intercourse. To put it in the context of fraud, the greater the risk of deprivation the higher the duty of disclosure. The failure to disclose HIV-positive status can lead to a devastating illness with fatal consequences. In those circumstances, there exists a positive duty to disclose. The nature and extent of the duty to disclose, if any, will always have to be considered in the context of the particular facts presented.[21]

It is here that the Court confronts one of the central difficulties posed by the case: when is there a duty to disclose, such that not disclosing will be "dishonest" in the opinion of a "reasonable person"? Having abandoned the traditional rule that only fraud as to the "nature and quality of the act" will vitiate consent, the Court must either accept that *any* fraud that induces a person's consent to participate in sex should vitiate that consent (as proposed by L'Heureux-Dubé J); or, alternatively, fashion some new, more "objective" rule defining the circumstances in which dishonesty will vitiate consent to sex. The majority prefers this latter approach.

Having concluded that not disclosing HIV-positive status may (at least in some circumstances) be "dishonest," and having intimated that there may not always be a duty to disclose, Cory J then considers the second requirement of fraud: "that the dishonesty result in deprivation, which may consist of actual harm or simply a risk of harm."[22]

Cory J thus posits a new, "harm"-based approach to defining fraud in the context of criminal assault, but cautions against an overly broad approach:

> Yet it cannot be any trivial harm or risk of harm that will satisfy this requirement in sexual assault cases where the activity would have been consensual if the consent had not been obtained by fraud. For example, the risk of minor scratches or of catching cold would not suffice to establish deprivation. What then should be required? In my view, the Crown will have to establish that the dishonest act (either falsehoods or failure to disclose) had the effect of exposing the person consenting to *a significant risk of serious bodily harm*. The risk of contracting AIDS as a result of engaging in unprotected intercourse would clearly meet that test. In this case the complainants were exposed to a significant risk of serious harm to their health. Indeed their very survival was placed in jeopardy. It is difficult to imagine a more significant risk or a more grievous bodily harm.[23] [emphasis added]

The phrase "significant risk of serious bodily harm" is the crux of the decision. Yet the vagueness of this test raises further questions for HIV-positive people,[24] while also suggesting possible limitations on the application of this precedent in future cases. The Court indicates there may be circumstances in which there is no duty to disclose:

> To have intercourse with a person who is HIV-positive will always present risks. Absolutely safe sex may be impossible. Yet the careful use of condoms might be found to so reduce the risk of harm that it could no longer be considered significant so that there might not be either deprivation or risk of deprivation [ie, harm or risk of harm]. To repeat, in circumstances such as those presented in this case, there must be a significant risk of serious bodily harm before the section can be satisfied. In the absence of those criteria, the duty to disclose will not arise."[25]

In imposing this objective limitation of *significant* risk of *serious* bodily harm on what constitutes fraud, the majority seeks to avoid what it considers to be the extremity of L'Heureux-Dubé J's subjective approach that any fraud that "induced the complainant to submit" to the act will vitiate consent and render the act an assault. McLachlin J also dismisses this approach by L'Heureux-Dubé J : "what constitutes deception is by its very nature highly subjective. One person's blandishment is another person's deceit, and on this theory, crime."[26]

The majority feels that such a subjective approach could trivialize the criminal process, because it would permit convictions for assault where a complainant's consent to sex was vitiated if the accused lied about such matters as his age, wealth, fidelity, love for the complainant, or sexual prowess:

> It is no doubt because of this potential trivialization that the former provisions of the *Code* required the fraud to be related to the nature and quality of the act. This was too restrictive. Yet some limitations on the concept of fraud as it applies to [the offence of assault] are clearly necessary or the courts would be overwhelmed and convictions under the sections would defy common sense. The existence of fraud should not vitiate consent unless there is a significant risk of serious harm. Fraud which leads to consent to a sexual act but which does not have that significant risk might ground a civil action. However, it should not provide the foundation for a conviction for sexual assault. The fraud required to vitiate consent for that offence must carry with it the risk of seri-

> ous harm. This is the standard which I think is appropriate and provides a reasonable balance between a position which would deny that the section could be applied in cases of fraud vitiating consent and that which would proliferate petty prosecutions by providing that any fraud which induces consent will vitiate that consent.[27]

In the majority's view, this standard is also "sufficient to encompass not only the risk of HIV infection but also other sexually transmitted diseases which constitute a significant risk of serious harm."[28]

An "Incremental" Approach: McLachlin J's Minority Opinion

In a minority opinion, McLachlin J (Gonthier J concurring) rejects the conclusion that Parliament's amendments to the *Criminal Code* intended to remove the existing common law limitations on fraud for the purposes of the assault offences. In her view, the broad changes contemplated by both Cory J and L'Heureux-Dubé J ignore recent decisions of the Supreme Court stating that courts should only effect changes to the common law where those changes are "incremental developments of existing principle and where the consequences of the change are contained and predictable."[29]

In her view, they are also undesirable: recognizing the overbreadth of his approach, Cory J "attempts to limit it by introducing an *ad hoc* qualifier: there must be a 'significant risk of serious bodily harm' before consent is vitiated."[30] But McLachlin J criticizes the majority for offering no theory as to why this, but not other deceptions coupled with a risk of harm, suffices to vitiate consent. More significantly, the test is unacceptably vague:

"Without disclosure of HIV status there cannot be a true consent. The consent cannot simply be to have sexual intercourse. Rather it must be consent to have intercourse with a partner who is HIV-positive."

> When is a risk significant enough to qualify conduct as criminal? In whose eyes is "significance" to be determined — the victim's, the accused's or the judge's? What is the ambit of "serious bodily harm"? Can a bright line be drawn between psychological harm and bodily harm, when the former may lead to depression, self-destructive behaviour and in extreme cases suicide? The criminal law must be certain. If it is uncertain, it cannot deter inappropriate conduct and loses its *raison d'être*. Equally serious, it becomes unfair. People who believe they are acting within the law may find themselves prosecuted, convicted, imprisoned and branded as criminals. Consequences as serious as these should not turn on the interpretation of vague terms like "significant" and "serious."[31]

McLachlin J also sees Cory J's extension of the criminal law of assault as unacceptably curtailing individual liberty:

> The equation of non-disclosure with lack of consent oversimplifies the complex and diverse nature of consent. People can and do cast caution to the winds in sexual situations. Where the consenting partner accepts the risk, non-disclosure cannot logically vitiate consent. Non-disclosure can vitiate consent only where there is an assumption that disclosure will be made, and that if HIV infection were disclosed, consent would be refused. Where a person consents to take a risk from the outset, non-disclosure is irrelevant to consent. Yet the proposed test would criminalize non-disclosure none the less. This effectively writes out consent as a defence to sexual assault in such cases [of non-disclosure]. The offence of sexual assault is replaced by a new offence – the offence of failure to disclose a serious risk.[32]

McLachlin J also adverts to the possible adverse impact of these broad extensions of the law on efforts to reduce the spread of HIV and other serious sexually transmitted diseases: because broad criminal sanctions are unlikely to be effective in encouraging people to come forward for testing and treatment, the burden will fall most heavily on marginalized groups, and a blanket duty to disclose may drive those with the disease underground.[33]

Yet it is not clear how McLachlin J's own position avoids either this problem or is any more principled than the majority's approach. She prefers an incremental approach that simply tacks on non-disclosure of HIV to the existing categories of "nature and quality of the act" and "identity of the accused" as a fraud that will vitiate consent to sexual activity:

"To have intercourse with a person who is HIV-positive will always present risks. Absolutely safe sex may be impossible. Yet the careful use of condoms might be found to so reduce the risk of harm that it could no longer be considered significant so that there might not be either [harm or risk of harm]."

> In the case at bar, I am satisfied that the current state of the law does not reflect the values of Canadian society. It is unrealistic, indeed shocking, to think that consent given to sex on the basis that one's partner is HIV-free stands unaffected by blatant deception on that matter. To put it another way, few would think the law should condone a person who has been asked whether he has HIV, lying about that fact in order to obtain consent. To say that such a person commits fraud vitiating consent, thereby rendering the contact an assault, seems right and logical.[34]

While regretting that "criminalizing deceit as to sexually transmitted disease inducing consent may prevent some people from seeking testing and treatment," McLachlin J also posits that:

> On the other hand, it may foster greater disclosure. The message that people must be honest about their communicable diseases is an important one. Conduct like that in the case at bar shocks the conscience and should permit of a criminal remedy. In addition, the proposed extension of the law is relatively narrow, catching only deceit as to venereal disease where it is established, beyond reasonable doubt, that there was a high risk of infection and that the defendant knew or ought to have known that the fraud actually induced consent to unprotected sex.... I conclude that the common law should be changed to permit deceit about sexually transmitted disease that induces consent to be treated as fraud vitiating consent under s. 265 of the *Criminal Code*.[35]

It should be noted that McLachlin J asserts here, without any further comment, that her proposed extension of the law would only apply where there is a "high risk" of infection, and the accused "knew or ought to have known" that not disclosing this actually induced the partner's consent to sex. There is no indication in her judgment as to why her approach would, in fact, be limited in this fashion (which sounds similar to the majority's "significant risk" test), or the principled basis for such a limitation.

Consent Following Disclosure Remains a Defence

Even if the accused's non-disclosure of HIV-positive status was "objectively dishonest," and there was a duty to disclose because the activity presented a "significant risk of serious bodily harm" – meaning that there has been a fraud that *could* vitiate consent to sex – the Court cautions that

> it must be emphasized that the Crown will still be required to prove beyond a reasonable doubt that the complainant would have refused to engage in unprotected sex with the accused if she had been advised that he was HIV-positive. As unlikely as that may appear it remains a real possibility. In the words of other decisions it remains a live issue.[36]

The Court thus implicitly rejected the Crown's argument that Cuerrier's partners' consent should be invalid for the "public policy" reason that the law should not recognize consent to "serious hurt or non-trivial bodily harm."[37]

What Does the Decision Mean for HIV-Positive People in the Context of Sex?

The decision raises numerous questions about consent to sexual activity for HIV-positive people and their partners, but offers no clear answers.

- Does a single act of unprotected sex carry a (legally) "significant" risk of transmitting HIV? Some sexual acts are riskier than others, and the risks are different for the different participants depending on which person is HIV-positive and what precautions are or are not taken.
- If a person's viral load is "undetectable," does this mean there is no (legally) "significant" risk of transmitting HIV to a sexual partner?
- Does it matter what strain of HIV the person has, since some may be more easily transmitted than others?
- What if the HIV-positive person says they want to practice "safer sex" (and even mentions the risk of HIV) but their partner refuses and the HIV-positive person can-

not ensure that precautions are taken? What if disclosing is unsafe or too difficult at that point?

- What if the HIV-positive person did not disclose their status where there was a "significant risk" of transmission (and therefore their partner's consent is not legally valid), but they honestly believed their partner was consenting to the sexual activity in question? The *Criminal Code* (s 273.2) says that a person charged with *sexual* assault can only rely on their belief in their partner's consent to sex as a defence if they took reasonable steps, in the circumstances known to them at the time, to determine that their partner was consenting. What "reasonable steps" are will depend on the circumstances. Might it be "reasonable" (at least in some circumstances) for the HIV-positive person to believe their partner is consenting to the sexual activity in question, even if it carries a risk (even a "significant" risk) of HIV infection? Will anything short of disclosure by an HIV-positive person (eg, discussing possible risks) be adequate "reasonable steps" in determining their partner's consent to risky sex? What if the HIV-positive person believed someone else had already told their sexual partner about their HIV status?
- The prosecution must also prove beyond a reasonable doubt that the complainant would have refused to engage in the risky activity if told about the HIV-positive person's status. If the HIV-positive person, without revealing their own status, raises the issue of possible HIV infection and their partner indicates they would engage in that activity with someone who is HIV-positive, this might prevent the HIV-positive person from being found guilty of assault if they do not disclose their own status before sex.

Does a Person with HIV/AIDS Have a Duty to Disclose outside the Sexual Context?

It remains to be seen what (if any) effect regarding disclosure the *Cuerrier* case may have for HIV-positive people outside the sexual context.

The Health-Care Setting

Physical contact is common between health-care workers and patients. In most, if not all, circumstances, *universal precautions* should be adequate to reduce the risk of transmitting HIV below the level of a (legally) "significant risk," meaning that an HIV-positive health-care worker would have no duty to disclose their HIV status to patients, and vice versa. But in the case of exposure-prone invasive procedures it could be held that there is a duty on the part of the HIV-positive health-care worker or patient to disclose their status before the procedure is conducted. HIV-positive health-care workers will also need to consider guidelines or policies developed by their professional regulatory body and/or their employer about when disclosure of HIV (and other conditions) may be required, and which procedures may be prohibited. Regardless of whether any given policy is appropriate, its interpretation could be affected by the Supreme Court's decision in *Cuerrier*.

Sharing Drug Injection Equipment

Unlike sex, sharing needles or other injection equipment does not necessarily involve direct physical contact creating a risk of transmitting HIV. Therefore, it would be unlikely that a charge of "assault" could be laid against the HIV-positive person who does not disclose their status to someone sharing their injection equipment. But the Court's decision in *Cuerrier* could affect the interpretation of other charges that might be laid in a case where an HIV-positive person shared needles without disclosing. If so, it may be that precautions (such as properly cleaning injection equipment) could reduce the risk of transmission enough so that it is not (legally) "significant," and so there would be no duty to disclose HIV-positive status. Again, whether this will be the case is unclear.

Information about HIV-Positive People Held by Others

The *Cuerrier* decision establishes that it *may* be a crime to not disclose one's HIV-positive status in circumstances where an activity poses a significant risk of transmission. What does this mean for those such as physicians, counsellors at AIDS service organizations, or researchers who hold information about a person's HIV-positive status and/or their conduct vis-à-vis others? Records of doctor/patient visits or counselling sessions may offer evidence that an HIV-positive person charged with assault was aware of their status before engaging in sex without disclosing, and was counselled about risk levels and modes of transmission. Counsellors might be told about the difficulties a person is having disclosing their status to a partner or partners, or difficulties in negotiating safer sex. This could constitute an admission of criminal activity, undermining the counselling relationship. In some circumstances, researchers might also have such information in their records or have this personal knowledge from research interviews. These physician, counsellor, or researcher records could be used to prosecute an HIV-positive person, and these people could be required to testify, revealing information that the accused person thought was to be kept confidential.

Where Do We Go from Here?

The Network is currently undertaking a project to analyze in more detail the possible ramifications of the *Cuerrier* decision, in consultation with people with HIV/AIDS, public health workers, physicians, ethicists, counsellors, and representatives from ASOs and other organizations serving HIV-positive people. A paper containing the results of the project will be published in April 1999.

– Richard Elliott

Richard Elliott is the author of *Criminal Law & HIV/AIDS: Final Report* and Director of Policy & Research of the Canadian HIV/AIDS Legal Network. Richard can be reached at <relliott@netrover.com>.

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[1] (1998), 127 CCC (3d) 1, rev'g (1996), 111 CCC (3d) 261, 141 DLR. (4th) 503 (BCCA), 3 CR (5th) 330, 136 WAC 295, 83 BCAC 295, 33 WCB (2d) 4, [1996] BCJ No 2229 (QL), aff'g 26 WCB (2d) 378 (BCSC). For background about the case, see: (1) Criminal Law Bulletin 1 (Update September 1998). The *Cuerrier* Case: A Summary. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, September 1998; and (2) R Elliott. Supreme Court to Hear *Cuerrier* Case. *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 1, 52-54.

[2] For a summary of some of these cases, see: R Elliott. *Criminal Law and HIV/AIDS: Final Report*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, March 1997; Criminal Law Bulletin 3: Canadian Criminal Case and HIV: An Overview. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1997; and other articles in this issue of the *Newsletter*.

[3] See Elliott, supra, note 2; B Bell. *Legal, Ethical and Human Rights Issues Raised by HIV/AIDS: Where Do We Go From Here? Planning for 1998-2003. A Planning Report.* January 1999. For an overview of various aspects of criminal law and HIV/AIDS in Canada, see also: Criminal Law Bulletins #1-8. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1997-1999.

[4] RSC 1985, c C-46, s 265(1).

[5] Ibid, s 268.

[6] Ibid, s 265(3)(c).

[7] [1991] OJ No 544 (Gen Div) (QL) (application for restraining order under *Health Protection and Promotion Act*); [1991] OJ No 1460 (Gen Div) (QL) (bail review hearing); (1992) 73 CCC (3d) 216 (Ont Ct Prov Div) (preliminary inquiry dismissing common nuisance and noxious thing charges); (1993), 81 CCC (3d) 257 (Ont Ct Gen Div) (directed verdict dismissing assault charges); [1993] OJ No 3273 (Gen Div) (QL) (decision not to deliver judgment). For a summary of the case, see Elliott, supra, note 2.

[8] (1996), 111 CCC (3d) 261 at 282 (per Prowse JA).

[9] In two earlier criminal cases, courts had reached the opposite conclusion: *R* v *Bennett* (1866), 4 F&F 1105, 176 ER 925; *R* v *Sinclair* (1867), 13 Cox CC 28. However, in a civil action for assault (and breach of promise to marry), a plaintiff was unsuccessful; the court held that mere concealment by her former lover of his venereal disease was not fraud so as to vitiate her consent to sex: *Hegarty* v *Shine* (1878), 14 Cox CC 145 (Ir CA).

[10] See *R* v *Harms* (1944), 81 CCC 4 (Sask CA); *R* v *Bolduc*, [1967] SCR 667; *R* v *Papadimitropoulos* (1957), 98 CLR 249 (HC Australia); *R* v *Maurantonio* (1968), 65 DLR (2d) 674 (Ont CA); *R* v *Petrozzi* (1987), 35 CCC (3d) 528 (BCCA). US courts, however, ruled that not disclosing the presence of "venereal disease" could constitute fraud that would vitiate consent to sexual intercourse: *State* v *Langford*, 102 A 63 (Del Ct Gen Sess, 1917); *State* v *Marcks*, 140 Mo 656 (1898). This principle was affirmed in the subsequent leading US case regarding civil liability for sexual transmission of a disease: *Kathleen K* v *Robert B*, 198 Cal Rptr 273 (Ct App, 1984).

[11] RSC 1970, c C-34, s 143.

[12] Ibid, s 149.

[13] RSC 1985, c C-46, ss 271-273.2.

[14] Ibid, s 265.

[15] *Petrozzi*, supra, note 10.

[16] *Cuerrier*, supra, note 1 at 44-45.

[17] *In re London and Globe Finance Corp*, [1903] 1 Ch 728; *Scott* v *Metropolitan Police Commissioner*, [1975] AC 819 (HL); *R* v *Olan*, [1978] 2 SCR 1175, 41 CCC (2d) 145, 86 DLR (3d) 212; *R* v *Théroux*, [1993] 2 SCR 5, 79 CCC (3d) 449, 100 DLR (4th) 624.

[18] *Cuerrier*, supra, note 1 at 47, citing: *R* v *Olan*, supra, note 17. *R* v *Théroux*, [1993] 2 SCR 5; *R* v *Zlatic*, [1993] 2 SCR 29.

[19] Ibid at 43.

[20] Ibid at 49.

[21] Ibid at 50.

[22] Ibid.

[23] Ibid.

[24] See: (1) Criminal Law and HIV/AIDS: Info Sheet 7. The *Cuerrier* Case: What Does It Mean for People with HIV/AIDS? Montréal: Canadian HIV/AIDS Legal Network, February 1998; and (2) Criminal Law and HIV/AIDS: Info Sheet 8. The *Cuerrier* Case: What does it mean for those with information about risky conduct by an HIV-positive person? Montréal: Canadian HIV/AIDS Legal Network, March 1998.

[25] *Cuerrier*, supra, note 1 at 50-51.

[26] Ibid at 29.

[27] *Cuerrier*, supra, note 1 at 51-52.

[28] Ibid.

[29] Ibid at 24-25, citing, inter alia: *R* v *Salituro*, [1991] 3 SCR 654, 68 CCC (3d) 289; *R* v *Seaboyer*, [1991] 2 SCR 577, 66 CCC (3d) 321, 83 DLR (4th) 193; *Winnipeg Child and Family Services (Northwest Area)* v *G(DF)*, [1997] 3 SCR 925, 152 DLR (4th) 193.

[30] Ibid at 26.

[31] Ibid at 26-27.

[32] Ibid at 27.

[33] Ibid at 29-30.

[34] Ibid at 33.

[35] Ibid at 36-37.

[36] Ibid at 51.

[37] This was the "public policy" limit on consent set out in *R* v *Jobidon*, [1991] 2 SCR 714, 66 CCC (3d) 454, 7 CR (4th) 233, 49 OAC 83, 128 NR 321, 14 WCB (2d) 27.

DISCRIMINATION

HIV/AIDS and Discrimination: A Discussion Paper

The Joint Project on Legal and Ethical Issues Raised by HIV/AIDS of the Canadian HIV/AIDS Legal Network and the Canadian AIDS Society released a discussion paper on HIV/AIDS and discrimination in 1998.[1] The paper shows that, more than 15 years after the beginning of the HIV/AIDS epidemic, stigma and discrimination remain pervasive in the lives of people with HIV/AIDS and populations affected by HIV/AIDS. In addition, it documents the impact of stigma and discrimination on the health and well-being of people with HIV/AIDS and populations affected by HIV/AIDS, and recommends basic elements of a concerted effort to prevent, redress, and eliminate HIV/AIDS-related stigma and discrimination. We reproduce a slightly edited version of the paper's executive summary.

Why a *Discussion Paper* on HIV/AIDS and Discrimination?

In 1995, during Phase I of the Joint Network/CAS Project on Legal and Ethical Issues Raised by HIV/AIDS, over sixty individuals and organizations identified discrimination as one of eight "top priority" legal and ethical issues raised by HIV/AIDS in Canada. Three years later, in January 1998, participants in a national workshop on discrimination and HIV/AIDS confirmed that:

- discrimination against people with HIV/AIDS is still pervasive in Canada;
- discrimination touches every aspect of the lives of people with HIV/AIDS;
- discrimination is becoming more subtle and harder to redress;
- discrimination has a significant impact on the health and well-being of people with HIV/AIDS and of populations affected by HIV/AIDS.

What Are the Issues?

First, although human rights statutes in Canada provide some essential basic protections for people with HIV/AIDS and populations affected by HIV/AIDS, a description and analysis of the experience of stigma and discrimination in the context of the HIV epidemic cannot be limited to attitudes and actions that are actionable under human rights law. Discrimination in the context of the HIV epidemic encompasses a broad range of attitudes and actions, including:

- stigmatizing attitudes as well as discriminatory actions;
- direct, indirect, and systemic forms of discrimination;
- anticipated discrimination as well as actual discrimination;
- legal forms of discrimination as well as illegal forms of discrimination;
- the private sphere as well as the public sphere; and
- stigma and discrimination that is related to HIV/AIDS (eg, based on sexual orientation or drug use) as well as stigma and discrimination that is directly a result of perceived or actual HIV status.

Discrimination against people with HIV/AIDS is still pervasive in Canada.

Second, the nature of the HIV epidemic in Canada in 1998 and of Canada's response to the epidemic have a bearing on stigma and discrimination as they are now experienced by people with HIV/AIDS:

- the epidemic is expanding, particularly among marginalized populations who typically experience many layers of stigma and discrimination – not only stigma and discrimination based on HIV status – and have few resources or little support in seeking redress;
- the restructuring of the health system and the devolution of authority for programs may result in fewer programs with a specific

> The advent of protease inhibitors and combination antiretroviral therapies has been accompanied by new forms of discrimination.

focus on HIV/AIDS, resulting in systemic neglect of needs that are unique to or disproportionately found among people with HIV/AIDS or populations affected by HIV/AIDS;

- the advent of protease inhibitors and combination antiretroviral therapies has been accompanied by new forms of discrimination, including restrictive assessments of disability, greater visibility at work and vulnerability to discrimination at work, inequitable access to therapies among diverse populations, and failure to observe guidelines regarding informed choice in HIV testing and treatment.

Third, while there are common elements in the experience of stigma and discrimination among the diverse populations affected by HIV/AIDS, there are also features that are specific to particular populations. Any response to stigma and discrimination in the context of the HIV epidemic must identify and address the specific ways in which stigma and discrimination affect gay and bisexual men, transgendered people, drug users, Aboriginal people, sex workers, prisoners, women, heterosexual men, children and their families, and youth.

What Does the *Discussion Paper* Contain?

The *Discussion Paper* reviews:

- definitions of discrimination that are current in Canada and internationally;
- the nature of stigma, discrimination, and vulnerability in the context of the HIV epidemic;
- stigma and discrimination that people with HIV/AIDS currently experience in their families and communities, at work, in housing, in health-care settings, in obtaining insurance coverage or benefits (particularly private medical and disability insurance), and in policies restricting travel or immigration;
- specific patterns of stigma and discrimination that populations affected by HIV/AIDS experience, and the impact of stigma and discrimination on their health and well-being in the context of the HIV/AIDS epidemic; and
- various ways to respond to stigma and discrimination, including education (public education, professional education, and focused education), redress (human rights law, the Canadian Charter of Rights and Freedoms, and other forms of legal or procedural redress), and advocacy.

What Are the Goals of the *Discussion Paper*?

The goals of the *Discussion Paper* are:

- to show how pervasive stigma and discrimination are in the lives of people with HIV/AIDS and populations affected by HIV/AIDS;
- to document the impact of stigma and discrimination on the health and well-being of people with HIV/AIDS and populations affected by HIV/AIDS; and
- to recommend basic elements of a concerted effort to prevent, redress, and eliminate HIV/AIDS-related stigma and discrimination.

> A concerted effort is required on the part of governments, human rights commissions, community and national organizations, professional associations, schools, workplaces, and researchers to prevent, redress, and eliminate stigma and discrimination associated with HIV/AIDS.

The *Discussion Paper* does not presume to be definitive in its description of HIV/AIDS-related stigma and discrimination, or in its recommendations as to how to respond to such stigma and discrimination. Rather, it is hoped that the *Discussion Paper* will stimulate:

- increased awareness of HIV/AIDS-related stigma and discrimination;
- further documentation of stigmatizing or discriminatory attitudes, actions, or systems;
- further analysis of the complexities and effects of HIV/AIDS-related stigma and discrimination;
- further discussion and deliberation on how to respond to HIV/AIDS-related stigma and discrimination; and
- increased resolve to address HIV/AIDS-related stigma and discrimination.

What Does the *Discussion Paper* Conclude?

The *Discussion Paper* concludes that, in addition to being unwarranted and unjust in most circumstances, discrimination against people with HIV/AIDS or populations affected by HIV/AIDS has serious consequences. These include (but are not limited to):

- vulnerability to HIV infection, particularly among young gay and bisexual men, drug users, Aboriginal people, prisoners, and sex workers;
- failure to prevent HIV infection, both among populations identified as being "at risk" for HIV infection and among populations not so identified;
- stress associated with HIV status, secrecy about HIV status, and social isolation because of HIV status – all adversely affecting the psychological health of people with HIV/AIDS;
- harassment from employers or colleagues; insufficient accommodation of health-related needs at work; reluctance to claim medical or disability benefits for fear of being harassed, laid off, or fired; being laid off or fired;
- denial of housing by landlords because of HIV status, sexual orientation, or source of income;
- reluctance to access health-care services, because of stigmatizing or discriminatory attitudes and remarks;
- delayed diagnosis and substandard treatment for HIV infection and HIV/AIDS-related diseases and opportunistic infections;
- insufficient or no insurance coverage for disability or drugs;
- exclusion from or underrepresentation in research on HIV/AIDS, resulting in insufficient information on HIV prevention, care, and treatment in certain populations; and
- restrictions on travel to foreign countries.

The *Discussion Paper* further concludes that a concerted effort is required on the part of governments, human rights commissions, community and national organizations, professional associations, schools, workplaces, and researchers to prevent, redress, and eliminate stigma and discrimination associated with HIV/AIDS. The *Discussion Paper* recommends that a framework for action on HIV/AIDS-related discrimination be developed in the Canadian Strategy on HIV/AIDS, with specific provision for:

- community participation in designing, implementing, and evaluating policies and programs;
- staff, protocols, systems, and networks to gather information on stigma and discrimination, analyze information, develop policy, and promote change in policies and practice;
- specialized legal services for people with HIV/AIDS and populations affected by HIV/AIDS, and a network of lawyers and legal clinics offering such specialized legal services;
- reviewing and recommending reforms to legislation and law enforcement practices that have an adverse effect on people with HIV/AIDS and populations affected by HIV/AIDS, to human rights legislation and procedures, and to human rights policies;
- public education aimed at reducing HIV/AIDS-related stigma and at creating a supportive environment for people with HIV/AIDS and populations affected by HIV/AIDS;
- education and training to promote and foster non-stigmatizing and non-discriminatory attitudes and practices among professionals, particularly those who provide care to people with HIV/AIDS on an occasional basis;
- education for children and youth, both in the schools and through alternative peer-based programs sponsored by social agencies and community organizations;
- initiatives to address HIV/AIDS-related harassment and discrimination in the workplace;
- efforts to increase participation of underrepresented populations in research, in identifying research priorities, in designing and implementing research projects, and in the ethical review of research; and
- a plan to monitor and evaluate annually efforts to prevent, redress, and eliminate HIV/AIDS-related discrimination.

The *Discussion Paper* notes, finally, that many of the issues raised by stigma and discrimination have been treated in recent reports on specific aspects of the HIV epidemic, namely, HIV testing and confidentiality;[2] criminal law and HIV/AIDS;[3] gay and lesbian legal issues and HIV/AIDS;[4] women and HIV/AIDS;[5] children and HIV/AIDS;[6] HIV/AIDS and injection drug use;[7] care, treatment, and support of injection drug users with HIV/AIDS;[8] street-involved people and HIV/AIDS;[9] prisoners and HIV/AIDS;[10] Aboriginal people and HIV/AIDS;[11] vocational and rehabilitation services; community-based prevention research; and research on HIV/AIDS and drug use. These reports, and their conclusions, recommendations, or guidelines, provide essential direction for policy and programs that will, along with achieving other objectives, reduce the extent and the impact of HIV/AIDS-related stigma and discrimination.

Continued from previous page.

The Discussion Paper has been sent to a broad range of individuals and organizations active in HIV/AIDS issues and human rights, and their comments and input have been solicited. Currently, the Canadian HIV/AIDS Legal Network is assessing what activities need to be undertaken in the short, mid and long term to ensure that the recommendations in the paper will be implemented. In addition, info sheets on HIV/AIDS-related stigma and discrimination have been developed and will be disseminated and become available on the Legal Network's website. These fact sheets summarize the contents of the Discussion Paper in an easy-to-read format.

For further information, contact Ralf Jürgens at 514 397-6828 ext 223; fax: 514 397-8570; email: <ralfj@aidslaw.ca>.

Copies of the *Discussion Paper* can be retrieved at the website of the Canadian HIV/AIDS Legal Network at www.aidslaw.ca or ordered through the National AIDS Clearinghouse. Tel: 613 725-3434; fax: 613 725-9826; email: <aids/sida@cpha.ca>.

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[1] T de Bruyn. *HIV/AIDS and Discrimination: A Discussion Paper.* Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998.

[2] R Jürgens. *HIV Testing and Confidentiality: Final Report.* Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998.

[3] R Elliott. *Criminal Law and HIV/AIDS: Final Report.* Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1997.

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[5] C Hankins, L Hum (eds). *Women and HIV National Workshop.* Montréal, 13-14 March 1995. Montréal: McGill AIDS Centre, 1995.

[6] RS Goldie et al. *Children Born to Mothers with HIV: Psychosocial Issues for Families in Canada Living with HIV/AIDS.* Toronto: The Hospital for Sick Children, 1997.

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

[8] D McAmmond. *Care, Treatment and Support for Injection Drug Users Living with HIV/AIDS.* A Consultation Report. Ottawa: Health Canada, March 1997.

[9] Canadian AIDS Society. *Sharing the Energy: A National Workshop on Street-Involved People and HIV/AIDS.* Ottawa: Canadian AIDS Society, 1995.

[10] R Jürgens. *HIV/AIDS in Prisons: Final Report*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1996.

[11] See the three papers by S Matiation summarized in this issue of the *Newsletter*.

Important Legal Victories for People with HIV/AIDS in the US

In a decision released on 25 June 1998 – the first decision by the Court to address legal questions raised by HIV/AIDS – the United States Supreme Court ruled by a majority of five to four that asymptomatic HIV infection can be covered as a disability under the *Americans with Disabilities Act* (ADA). However, the Court remanded the complaint for further hearing on the question of whether an HIV-positive dental patient would present a "direct threat" of injury to a dentist. In a subsequent decision in the case, the US Court of Appeals for the First Circuit ruled on 29 December 1998 that Maine dentist Randon Bragdon unlawfully discriminated against Sidney Abbott, an asymptomatic HIV-positive patient, by refusing to fill her cavity in his dental office. The following note briefly summarizes the decisions and explains why they are so important.

Background

In the last issue of the *Newsletter* we reported about recent developments in the law that have created cause for alarm:

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

We summarized a number of decisions by US courts that limited protection against discrimination for persons with asymptomatic HIV and concluded by citing Parmet and Jackson, who said that

> [p]erhaps HIV will eventually lose its power both to kill and to arouse social discrimination. At that time, when both the physical and social conditions that have made HIV a disability are gone, neither individuals nor the public health will require the protection of disability law. Until that time, however, a doctrine that views HIV as no longer a disability is dangerous.[2]

The Supreme Court Case

In the case of *Bragdon* v *Abbott*,[3] the Supreme Court has since had an opportunity to clarify the application of the ADA to people with HIV. The Court ruled that Abbott, an asymptomatic HIV-positive woman who was refused treatment in a dentist's surgery, met the requirements for disability due to her infection. The ADA requires that a "major life activity" be impaired in order for the condition to be covered.

Abbott's argument – that reproduction is a major life activity, and that HIV infection imposes a substantial limitation on her ability to engage in such activity – was accepted by the majority, who ruled that reproduction is indeed a "major life activity."

However, because the Court is constitutionally limited to deciding actual cases, it did not address the more general question of whether HIV infection is, per se, a disability. Nevertheless, Justice Kennedy, writing for the Court, noted:

> Given the pervasive, and invariably fatal, course of the disease, its effect on major life activities of many sorts might have been relevant to our inquiry. Respondent and a number of amici make arguments about HIV's profound impact on almost every phase of the infected person's life. In light of these submissions, it may seem legalistic to circumscribe our discussion to the activity of reproduction.

But because the lower courts had dealt solely with reproduction, Kennedy said, the Court would follow its practice of speaking only to the issues properly raised on appeal. Therefore, as noted in a summary of the decision published elsewhere,[4] there was some speculation after the decision was announced that the Court's narrow treatment of the disability issue left open the question of whether an HIV-positive gay man who had never expressed an interest in having children, or an HIV-positive individual who was otherwise incapable of reproductive activity, would be protected by the ADA. On this point, Leonard comments:

> Kennedy's dicta, reinforced by a short concurring opinion in which Justice Ginsburg enumerated the array of activities affected by HIV infection, suggested that the lower courts should recognize virtually all persons with HIV infection as being covered under the statute. Although the Court noted that Abbott stated her decision to refrain from having children, the opinion did not seem to rest heavily on that point. Also, the analytical method Kennedy followed suggested that a majority of the Court was generally receptive to a broad construction of the definition of disability. ... And if there were any doubts about the broader effect of the ruling, Kennedy added two points that suggested such a broader effect. First, he noted that agencies and courts had construed the *Rehabilitation Act*'s relevant provisions to apply to HIV infection, and observed that Congress had expressly provided that the ADA should be construed to be at least as protective as the earlier statute. Second, he noted the broad reading that regulatory agencies have given to the definition of disability, emphasizing the deference that the Court normally pays to such interpretations.[5]

However, the Court expressed reservations about the lower courts' consideration of the evidence on the degree of risk a dentist would face in filling a cavity for an HIV-positive person. The ADA provides an affirmative defence for cases in which the disability creates a significant risk of harm to others. In its earlier decision, the First Circuit had relied heavily on two documents to conclude that as of 1994 a reasonable dentist would not believe that filling Abbott's cavity in his office presented a significant risk. First, the US Centers for Disease Control had issued guidelines stating that it would be safe to provide dental care to people with HIV if universal precautions were observed. Second, the American Dental Association had issued a policy statement contending that it was safe for dentists to care for people with HIV. The Supreme Court questioned whether the CDC guidelines had adequately addressed the issue of significant risk, and whether the Dental Association policy was inspired more by ethical concerns than scientific evidence, and sent the case back to the First Circuit for further consideration.

The First Circuit's Judgment

The First Circuit made short work of the case, hearing new arguments from the parties on 9 December and issuing its decision only three weeks later. Writing for a unanimous panel, Judge Selva found that the CDC guidelines in effect in 1994 were a continuation of a series of CDC pronouncements on this issue, all advising that dentists could safely treat patients if they used universal precautions.[6] And Judge Selva found that the American Dental Association policy was the work of a scientific panel, not the professional ethics board. He also found that Bragdon had failed to provide any evidence that would give a reasonable basis for him to have doubted the safety of the procedures he was being asked to perform.

The Significance of the Decisions

The Supreme Court's decision establishes that HIV-positive women of childbearing capacity are protected against discrimination by the ADA, The First Circuit decided that health-care workers have an obligation under the Americans with Disabilities Act to perform invasive procedures that may involve blood exposure upon HIV-positive patients.

and that most probably so is everybody else who lives with HIV, regardless of whether they are symptomatic or not. The First Circuit then decided that health-care workers have an obligation under the ADA to perform invasive procedures that may involve blood exposure on HIV-positive patients – to refuse to do so would discriminate against the HIV-positive patient.

These decisions afford much-needed protection to people with HIV/AIDS in the US, where AIDS stigma and discrimination remain prevalent, as revealed by a recent study undertaken by Herek.[7] The study assessed the prevalence of AIDS stigma in 1997, and compared current levels with those assessed in a 1990-91 survey.[8] It concluded that, although its manifestations have changed in some respects during the 1990s, AIDS stigma persists in the US:

> Support for blatantly stigmatizing policies has decreased, but support remains high for mandatory testing of specific groups. A significant minority of the public expressed discomfort at the prospect of personal contact with PWAs. AIDS continues to be a strongly symbolic issue, with much of the US public associating AIDS with gay and bisexual men. Moreover, stigma is more strongly expressed against gay or bisexual men who contracted HIV sexually, compared to heterosexual PWAs.[9]

The understanding that HIV cannot be transmitted through casual social contact appears to be eroding.

The study further showed that "the understanding that HIV cannot be transmitted through casual social contact appears to be eroding, possibly because public health campaigns in the United States have not reinforced this belief in recent years." Fifty-five percent of 1712 randomly selected participants in the study believed that it was possible to contract HIV from using the same drinking glass as a person with HIV/AIDS, 41 percent believed that it might be contracted from a public toilet, and 54 percent believed that HIV might be transmitted through a cough or sneeze.

The study highlighted the continuing prevalence of AIDS stigma in the US and, by extension, the continued importance of affording adequate protection against unjustified discrimination to people with HIV/AIDS. People with HIV/AIDS need to be confident that discrimination on the job, in public accommodation, and by governments remains illegal. The two recent decisions by US courts have restored some of that confidence.

– Ralf Jürgens

Ralf Jürgens is Executive Director of the Canadian HIV/AIDS Legal Network, Chair of the Interagency Coalition on AIDS and Development, Editor of this *Newsletter*, and a member of the Ministerial Council on HIV/AIDS. He can be reached at <ralfj@aidslaw.ca>.

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[1] R Jürgens. Your Health Is Back. Now You May Lose Your Protection against Discrimination. *Canadian HIV/AIDS Policy & Law Newsletter* 1997/98; 3(4)/4(1): 3-5 at 3, with reference to WE Parmet, DJ Jackson. No Longer Disabled: The Legal Impact of the New Social Construction of HIV. *American Journal of Law & Medicine* 1997; 23(1): 8-43 at 40.

[2] Jürgens, supra, note 1, with reference to Parmet & Jackson, supra, note 1 at 43.

[3] 118 S Ct 2196 (US 1998).

[4] AS Leonard. Supreme Court Rules 5-4 that "Asymptomatic" HIV-Infection May Be Covered as a Disability by ADA. *Lesbian/Gay Law Notes* Summer 1998: 101-103 at 102.

[5] Ibid.

[6] *Abbott v Bragdon*, 1998 WL 887125. Most of the following summary of the judgment has been taken from AS Leonard. 1st Circuit Reaffirms Summary Judgment for Sidney Abbott. *Lesbian/Gay Law Notes* January 1999: 10.

[7] GM Herek. AIDS Stigma and HIV-Related Beliefs in the United States: Results from a National Telephone Survey. Abstract no 44173, presented at the 12th World AIDS Conference, Geneva, 1998.

[8] GM Herek, JP Capitanio. Public Reaction to AIDS in the United States: A Second Decade of Stigma. *American Journal of Public Health* 1993; 83(4): 574-577.

[9] Supra, note 6. This information is taken from a handout distributed at the conference. For more information, Gregory Herek can be reached at the Department of Psychology, University of California, 1 Shields Avenue, Davis, CA 95616-8775 USA. Email: <psychology@pobox.com>.

ABORIGINAL PEOPLE AND HIV/AIDS

"Where Are My Human Rights?": Aboriginal People and HIV/AIDS

After discussing economic conditions in a number of reserve communities and describing the racism he has experienced during his life, one person interviewed for a joint project between the Canadian HIV/AIDS Legal Network (Network) and the Canadian Aboriginal AIDS Network (CAAN) on "HIV/AIDS and Aboriginal People: Legal Issues" asked, "Where are my human rights?" The project has shown how the systemic and individualized discrimination experienced by Aboriginal people generally, and by Aboriginal people with HIV/AIDS in particular, contributes to the disproportionate impact of HIV/AIDS on Aboriginal communities. It has also highlighted problems of jurisdiction and funding that create barriers to the development and delivery of coordinated and comprehensive HIV/AIDS programs and services for Aboriginal people, and drawn attention to problems related to HIV testing and confidentiality for Aboriginal people.

The Crisis of HIV/AIDS among Aboriginal People

The number of cases of HIV and AIDS is rising dramatically in the Aboriginal population. In its May 1998 edition of *Epi Update: HIV/AIDS Epidemiology Among Aboriginal People in Canada*,[1] the Laboratory Centre for Disease Control (LCDC) reports that the proportion of AIDS cases attributed to Aboriginal people increased from two percent before 1989 to more than ten percent in 1996-97. Based on the reports of Aboriginal HIV/AIDS workers and organizations, and the prevalence of risk factors among Aboriginal people, there is an HIV/AIDS epidemic that threatens to have a serious impact on First Nations, Métis, and Inuit communities.

The Project on Legal Issues

The Network started work on legal issues relating to Aboriginal people and HIV/AIDS in the summer of 1997.[2] Three discussion papers were released in March 1998, based on discussions with key informants working in the field of Aboriginal people and HIV/AIDS: *Discrimination, HIV/AIDS and Aboriginal People; HIV/AIDS and Aboriginal People: Problems of Jurisdiction and Funding*; and *HIV Testing and Confidentiality: Issues for the Aboriginal Community*. In December 1998 the Network and CAAN agreed to work jointly to produce fact sheets based on the issues addressed in the discussion papers. In addition, follow-up discussions were conducted in January and February 1999 about the issues addressed in the three papers, and revisions were made to the papers. The revised papers were published in March 1999. The following text briefly summarizes some of the main issues raised in the papers.

> There is an HIV/AIDS epidemic that threatens to have a serious impact on First Nations, Métis, and Inuit communities.

Discrimination, HIV/AIDS and Aboriginal People

Background

Aboriginal people living with or affected by HIV/AIDS face discrimination in many of the same ways that non-Aboriginal people do. What differentiates discrimination against Aboriginal people living with HIV/AIDS is the history of oppression, racism, and social disintegration experienced by First Nations, Métis, and Inuit communities. It is in the context of Aboriginal oppression in Canada that the issue of discrimination against Aboriginal people living with or affected by HIV/AIDS must be approached.

The stories told by those consulted for the paper suggest that discrimination against Aboriginal people living with HIV/AIDS comes from a variety of sources, including some band administrators and community members, health practitioners, and the public at large. Discrimination is often associated with misunderstandings or lack of knowledge about HIV/AIDS and is often reinforced by other social problems and other forms of discrimination.

Issues

A number of approaches to improving the human rights situation of Aboriginal people living with or affected by HIV/AIDS were suggested throughout the discussions undertaken during the preparation of the papers. Significantly, very few of those consulted, particularly from the Aboriginal community, expressed much faith in human rights legislation.

Legal responses to discrimination usually involve filing a complaint and engaging in an adversarial dispute resolution process. For a variety of reasons, this approach is not often used by Aboriginal people, particularly those who experience HIV/AIDS-related discrimination.

Issues involving the human rights system include:

- the application of federal and provincial human rights legislation to Aboriginal people and the application of the Charter to Aboriginal governments;
- the impact of s 67 of the Canadian Human Rights Act on the human rights protections of Aboriginal people (s 67 acts as a shield against complaints based on discrimination flowing from the *Indian Act* or from actions taken pursuant to the *Indian Act*, including some actions of band councils and Indian and Northern Affairs Canada); and
- weaknesses in the human rights system, particularly for Aboriginal complainants, including weaknesses in Charter litigation.

A number of non-legal approaches to the problem of discrimination against Aboriginal people living with or affected by HIV/AIDS were raised during the consultations. Virtually all those interviewed referred to the need for education efforts to continue in all First Nations, Métis, and Inuit communities, and to the importance of increasing the involvement of leaders in HIV/AIDS issues. Further, it was suggested that non-Aboriginal practitioners, educators, and others working in the field of HIV/AIDS need to develop a better knowledge and understanding of Aboriginal living conditions, cultures, and traditions. It was also emphasized that Aboriginal people should be involved in all aspects of the control, design, and direction of HIV/AIDS initiatives for Aboriginal people.

Problems of Jurisdiction and Funding

Background

The spread of HIV/AIDS within the Aboriginal community across jurisdictional boundaries has focused attention on the need to reduce the detrimental impact of these boundaries on the development and delivery of effective HIV/AIDS programs and services.

The issue of jurisdiction with respect to Aboriginal people is complicated. It does not end with the constitutional division of powers, but involves the historical relationship between the Crown and First Nations, treaties and land claims agreements, the *Indian Act*, ss 25 and 35 of the *Constitution Act, 1982*, the concept of fiduciary duty, judicial decisions, and the transition to self-government. Conflict concerning the boundaries between the powers and responsibilities of the orders of government, including Aboriginal governments, often results in a policy vacuum that hampers the implementation of an effective response to HIV/AIDS.

Issues

Discussions conducted for this paper addressed a number of developments in health care that raise concerns for Aboriginal people living with or affected by HIV/AIDS. The following changes in health care are particularly relevant to HIV/AIDS and Aboriginal communities:

- the devolution of authority over health care to the provinces and territories and the regionalization within provinces and territories of health services; and
- the transfer by the federal government of authority over health services to First Nations and some Inuit communities. This transfer does not respond to the needs of off-reserve and non-status Indians; indeed, it is often detrimental to these groups.

The following issues relating to jurisdiction, HIV/AIDS and

Aboriginal people were raised during the discussions for the paper:

- funding problems, including (in)adequacy and sources of funding;
- the impact of divisions between federal and provincial/territorial governments on the development and delivery of coordinated and comprehensive HIV/AIDS programs and services for Aboriginal people;
- the impact of interdepartmental barriers on coordination and collaboration; and
- the impact of divisions within the Aboriginal community due to the legacy of imposed definitions and jurisdictional divisions.

Some initiatives are presently underway to improve collaboration and coordination between federal and provincial/territorial government agencies working in the field of HIV/AIDS, and between departments and branches within government bureaucracies dealing with Aboriginal issues. The value of these initiatives is reinforced where Aboriginal participation in discussion and decision-making is supported.

Provincial and national Aboriginal HIV/AIDS strategies are another source of increasing collaboration and coordination in the area of Aboriginal people and HIV/AIDS. Following the example of Ontario and British Columbia, the development and implementation of such strategies in other provinces and territories could be beneficial to Aboriginal people.

The announcement that a focus on Aboriginal communities is a program component in the Canadian Strategy on HIV/AIDS (CSHA) is welcome. However, the commitment of funding to Aboriginal communities under the CSHA is only a beginning in the development of a coordinated and comprehensive response to HIV/AIDS in the Aboriginal population.

HIV Testing and Confidentiality

Background

Many of the people interviewed for the testing and confidentiality paper expressed concern about the low number of First Nations people and Inuit who seek HIV testing. The low number seeking testing means that Aboriginal people with HIV/AIDS are often diagnosed and first receive treatment at later stages in their illness than other people with HIV/AIDS.

Approaches to promoting HIV testing among Aboriginal people must address broader issues, including racism in health services, the prevalence of low self-esteem among some Aboriginal people, particularly in some subgroups such as street-involved people, and problems of confidentiality in small communities.

Issues

In Canada a consensus emerged in the late 1980s that, except in a few well-defined circumstances, people should be tested for HIV only with their informed, voluntary and specific consent, when counseling and education before and following testing are available and offered, and when confidentiality of results or anonymity of testing can be guaranteed.[3] Despite the consensus around these issues, opinion on several other issues related to testing has remained divided. In addition, there are a number of issues that, although in theory consensus was reached, in practice remain unresolved. For example:

- access to testing remains a problem for many people;
- testing for HIV without the specific informed consent of the person being tested is allegedly taking place more frequently;
- many people often do not receive adequate counseling; and
- calls for mandatory or compulsory testing of certain groups of the population continue.[4]

These issues are as relevant to Aboriginal people as to the general population of Canada. However, an examination of the issues must start from a different context. The oppression and racism experienced by the Aboriginal community has contributed to the overrepresentation of Aboriginal people among the most marginalized groups in Canada and to problems of ill-health. These factors make many Aboriginal people more vulnerable to HIV.

Based on the interviews conducted for this paper, the following issues are particularly relevant to Aboriginal people:

- control and ownership of research and data involving Aboriginal people;
- accessible options for HIV testing that overcome problems of remoteness, cultural difference, and reluctance to use mainstream facilities;
- culturally appropriate pre- and post-test counseling; and
- confidentiality in small communities.

Aboriginal people living with or affected by HIV/AIDS continue to experience discrimination. While early detection of HIV infection is a pressing priority, it would be a mistake to dismiss the importance of respecting people's rights to confi-

The federal and provincial/territorial governments in Canada have been slow to recognize and support Aboriginal people in their efforts to rebuild their communities.

dentiality and of the risk of discrimination. Arguments in favour of accessible testing based on specific informed consent, accompanied by quality pre- and post-test counselling, and under conditions of confidentiality, are as pertinent to Aboriginal people as to anyone else. To date, however, the HIV testing available to Aboriginal people falls short of the ideal for a variety of reasons. In order to reduce the impact of HIV on Aboriginal people and provide timely care, treatment and support for those already living with HIV/AIDS and who are not aware of it, barriers to HIV testing for Aboriginal people must be eliminated.

Conclusions

The three papers contain over thirty conclusions – too many to list in this article. However, three central themes can be drawn from the papers.

A Context of Racism and Oppression

Aboriginal people have experienced a legacy of racism and oppression that has devastating effects. In too many ways, Aboriginal people continue to have to deal with problems associated with this experience. A response to the HIV/AIDS epidemic in Aboriginal communities must begin with an understanding of the experience of Aboriginal people in Canada and must include consideration of other social, cultural, economic, and political issues.

An Epidemic during a Period of Transition

Despite the legacy of racism and oppression, a resurgence in the vitality of Aboriginal communities is underway. This resurgence is bringing with it many positive changes. There are many issues, however, that continue to require attention and action. The federal and provincial/territorial governments in Canada have been slow to recognize and support Aboriginal people in their efforts to rebuild their communities. Slow progress is being made toward self-government and improved health and social conditions among Aboriginal people.

The success of HIV/AIDS programs and services for Aboriginal people will depend on the extent to which Aboriginal expertise guides, directs, and implements the process.

There is a risk that some people and some issues might be overlooked during this period of transition. Discrimination related to HIV/AIDS makes this risk that much greater. It is imperative that attention be directed toward HIV/AIDS issues for Aboriginal people and the ways the variety of changes underway may affect HIV/AIDS programs and services.

Aboriginal Expertise

The driving force behind the resurgence in Aboriginal culture and identity has come from within Aboriginal communities themselves. The success of HIV/AIDS programs and services for Aboriginal people will depend on the extent to which Aboriginal expertise guides, directs, and implements the process.

Due to their personal experience with HIV/AIDS, Aboriginal AIDS workers and Aboriginal people living with or affected by HIV/AIDS have a particularly significant contribution to make to the development of a comprehensive framework addressing HIV/AIDS issues for Aboriginal people. Their work must be supported by all levels of government and reinforced by the leadership in Aboriginal communities.

– Stefan Matiation

Stefan Matiation has worked on contract for the Canadian HIV/AIDS Legal Network, as researcher on the project on legal issues relating to Aboriginal people and HIV/AIDS. Stefan can be reached at <henmat@magma.ca>.

The revised discussion papers (*Discrimination, HIV/AIDS and Aboriginal People: A Discussion Paper; HIV Testing and Confidentiality: Issues for the Aboriginal Community*; and *HIV/AIDS and Aboriginal People: Problems of Jurisdiction and Funding*) are available through the Canadian HIV/AIDS Clearinghouse (Tel: (613) 725-3434; email: aids/sida@cpha.ca) and CAAN (Tel: (613) 567-1817; fax: (613) 567-4652; email: caan@storm.ca) and on the Network's website at <www.aidslaw.ca>.

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[1] LCDC. *Epi Update: HIV/AIDS Epidemiology Among Aboriginal People in Canada*. Health Canada, May 1998.

[2] See S Matiation. HIV/AIDS and Aboriginal People: Legal Issues. *Canadian HIV/AIDS Policy & Law Newsletter* 1997/98; 3(4)/4(1): 17-18.

[3] For more details, see R Jürgens. *HIV Testing and Confidentiality: Final Report*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998.

[4] Ibid.

PUBLIC HEALTH

Lessons from Krever – A Personal Perspective

The following paper was prepared for a meeting on Future Directions for Communicable Disease Control in Canada's Public Health System, held in Vancouver on 21-22 January 1999. The purpose of the meeting was to consider implications of the Final Report of the Commission of Inquiry on the Blood System in Canada (the Krever Report) for communicable disease control within the context of health protection in Canada's public health system. About 50 people attended, including provincial/territorial Medical Officers of Health (MOHs), epidemiologists and provincial laboratory directors, as well as representatives of public health nursing, public health inspection, regional and local MOHs, regulators, the Laboratory Centre for Disease Control (LCDC), and national organizations such as the Canadian Blood Service, the Canadian Public Health Association, and the Canadian HIV/AIDS Legal Network. In his paper, Jan Skirrow describes the increasing role that governments and politics have played over the years in the management of Canada's health-care system, which the Krever Report identified as one of the underlying factors that led to the problems that Canada experienced with its blood system in the 1980s. The paper discusses nine lessons for public health that emerge from the Krever Report. It concludes that fundamental deficiencies in the system may result in another public health tragedy such as the one that ought to have been prevented. It cites the current epidemic of death and disease among Canada's injection drug use community as an example of a public health tragedy in the making.

Introduction

The Commission of Inquiry on the Blood System in Canada chaired by Mr Justice Horace Krever, (the Krever Inquiry) was established to examine what its Final Report[1] refers to as "a public health disaster that was unprecedented in Canada."

The Final Report makes a number of recommendations intended to ensure the future safety of Canada's blood supply. It also tells a story of the events and people that were part of this public health disaster. It notes that "only by knowing the complete story ... can [one] fully understand the systemic shortcomings and their consequences, and the reforms that are necessary."

The story provided by Justice Krever has lessons for the public health community that go well beyond the specifics of the blood disaster. It is a compelling and unsettling tale of a way of doing things that lay at the heart of the blood problem. In my opinion, this maladaptive approach was not and is not confined to Canada's blood system. It is deeply embedded in many of our public institutions.

I was heavily involved with health-related federal/provincial bodies for many years, including the interval examined by the Krever Inquiry. Thus what follows is a personal reflection upon the events outlined in the Final Report. Although I intend otherwise, this paper may do little more than reveal a yawning chasm. On the one bank are public service executives, the best of whom strive to get things done despite a byzantine, power-driven and unresponsive system. On the other bank are public health professionals, who are often public servants as well, puzzled that science and reason have so little apparent impact on government decision-making.

The Historical Context

There has been a broad and continuing shift in power over this century from individuals and private organizations to governments, and a changing power balance between the federal government and local/provincial authorities. This period of change has been accompanied by an acceleration in the complexity of public issues that has seriously tested the methods Canada has used in the past to ensure coherent action on emergent problems.

Older ways of delivering many social and health services emphasized private practitioners and small, local charitable, religious, or voluntary organizations, with minimal government involvement. In the past half century this has changed profoundly. Example: The cost of health-related services has risen in response to many factors. As costs rose, government provided an attractive means of financing what the public demanded, and in a way consistent with Canadian values. However, with public funding came increased government involvement and, inevitably, control.

Politics – which has more to do with process and appearance than results – has thus played an ever larger role in what previously were scientific or technical matters. The aims and values of politicians are in some key aspects the antithesis of those of scientists and health practitioners. Relations between health professionals and political decisionmakers have increasingly been mediated by public service executives. Their role is a difficult one. Health professionals expect public servants to carry their scientific message without dilution or editorial comment. Politicians expect those bringing the message to help them understand the technical message in the practical terms that a politician will use to arrive at a political judgment. The blood problem as detailed by the Krever Inquiry reflects these historical shifts as fundamental underlying factors.

There are a number of interrelated lessons that I believe emerge from the Final Report.

Lesson One – The Canadian Way

One important lesson is the extent to which the blood tragedy was facilitated by how problems and issues were approached when the blood system was vulnerable. Canadians have developed values and a way of doing things that tolerate difference and polite dissent, emphasize agreement and consensus, but avoid the confrontation and enthusiastic discourse often found among our American cousins. Canada's ability to stay united in the face of fundamentally divisive national issues is a tribute to the power of our approach.

However, the "Canadian Way" is so entrenched in our public institutions, and in ourselves, that we fail to recognize how counterproductive it can be. Our approach is not very useful when the problems are technical rather than political, develop fairly rapidly, involve matters beyond the personal experience of decision-makers, or are value-loaded. This was clearly the case with HIV/AIDS and Canada's blood supply in the 1980s. Canada has embraced a process-bound approach that has been effective at managing (but rarely resolving) our political differences, but that is patently unable to respond in a timely or appropriate manner when speedy resolution of a difficult issue must be reached.

Almost anyone or anything can stop or delay action on almost any issue. Seeking consensus, much less unanimity, is very difficult. At Ministers and Deputy Ministers of Health meetings that I attended, any significant dissent on an issue usually meant, at best, deferral to the next meeting, usually six months off. The formal agenda, frequently containing urgent and important matters, was often set aside in order to discuss a crisis, usually fiscal or political, and sometimes precipitated by a previous failure to deal with an urgent item.

We must question our automatic response when faced with a difficult issue: strike a committee or task force, engage in wide consultations, set up oversight or coordinating committees, avoid conflict, postpone action until consensus is achieved, and so on. While these mechanisms are legitimate in many situations, they all too often serve only to create inflexibility, delay action, inflate cost, and drive the participants to distraction.

We also need to strengthen the informal, working-level exchanges of information, problem alerts, and field experience that is often lost when we depend on formal mechanisms. Most health and government institutions emphasize structure and process, and many health professionals and public servants are most comfortable with the predictability of such systems. Yet we must develop flexibility in communication and consultation despite institutional barriers. This flexibility must extend across the chasm I described previously. It may well be easier to talk only with those on your side of the divide, but it may be more useful to attempt to build bridges.

Lesson Two – The Connection between Values, Expectations and Results

The Final Report reveals organizational values and principles in conflict with desired outcomes. Principle-driven organizations such as the Red Cross cannot have conflicting values or expectations imposed without serious consequences. Such consequences are rarely thought through.

Example: All parties to the blood tragedy insisted on unpaid donors and a "made in Canada" product. Yet no one seems to have thought through the implications of strict adherence to these values at a time when the blood system was increasingly unable to provide needed products. Either the values should have been seriously questioned, or the blood collection system redesigned, or both. Instead, the values were supported, and nothing done to increase the ability of the blood system to function under them.

Example: The Red Cross was determined to protect its independence. This is consistent with the values and history of that organization. At the same time, its dependence on government funding for the blood system meant that this status was not sustainable. This irresolvable value clash made the Red Cross's continuing stewardship of the blood system untenable. Yet this wasn't considered until much too late.

The health sector is littered with this kind of issue. Examples: strong political and public support for the concept of individual and population-based interventions intended to reduce the incidence of preventable diseases does not translate into a willingness to support in any significant way the necessary policy and program development research; strong public and political commitment to "free" health services, combined with an unwillingness to support the necessary tax levels; strong political commitment to a "single-tier" system, combined with growing alternatives for well-off Canadians. The consequences play out daily within our stressed health care system. Each of us should be alert to such conflicts. They are not semantic issues and are among the most destructive forces we face.

Lesson Three – Territory and Power: Who Speaks for the Public?

Issues of territoriality and power subverted the integrity of Canada's blood system. Over the period explored in the Final Report, such issues came to dominate the relationship between Connaught Labs and the Red Cross, and were prominent in the competing industrial and economic development objectives of several provinces, and in the interactions between the many involved committees, regulators, and bureaucrats.

The vital interests of those dependent upon the blood system were rarely considered. Essential information was withheld from the public for far too long on the basis that it might alarm or offend someone, or possibly reduce blood donation levels.

In my own experience as a senior health executive, rarely is the end recipient of our services the subject of serious discussion. Rarely is the consequence of failure for the people we supposedly serve considered in concrete terms.

The Final Report suggests that physicians speak for patients as part of their involvement with federal-provincial and other administrative bodies. However, an increasing proportion of executive health-sector positions are held by non-physicians, and this is unlikely to change anytime soon. Thus, I believe that all those involved in decisions that affect the health and welfare of others must assume responsibility for ensuring that all possible consequences for the end-recipient are adequately considered.

The failure of Canada's blood system came about partly because people accepted, without question, the opinions and reassurances of supposed experts. Thus, in addition to being willing to act as patient advocates, all health professionals have an obligation to develop a capacity to exercise independent judgment about information obtained from presumed experts.

Health professionals have an obligation to explain to their executive or political masters, in understandable language, the essence of an issue and provide a realistic assessment of consequences. It is not adequate to say "trust me - I know." Equally, it is not useful to overstate the potential negative consequences of not doing what you recommend, in the hope of forcing acquiescence. The first approach widens the chasm I described earlier; the second increases the likelihood that future warnings will have little credibility.

Lesson Four – Organizational Chaos

The decade examined by the Krever Inquiry was one of constant organizational change in almost all government health departments, with rapid turnover of Deputy Ministers and other senior staff. Within a two-year period, almost all of the faces at Deputy meetings changed, and some more than once.

One consequence was a lack of continuity such that no one on many senior committees had any prior personal experience of the matters under consideration. The near certainty of short tenure did not favour the kind of digging in, understanding and hard work necessary to good problem analysis and resolution. Too much time was wasted on trying to find a way to work within a constantly shifting structure and briefing new players.

Another consequence was overwork. Downsizing, combined with the ultimately non-productive work of constantly reinventing the organization, meant that all staff were overwhelmed. The Krever Inquiry suggests this as one reason for lapses in the regulatory framework that might otherwise have caught the developing blood crisis earlier. Overworked people rarely take on new tasks if any rationale can be found to avoid them.

Most worrisome is that this situation has worsened in the past few years in virtually all Canadian jurisdictions. The lack of capacity in what remains of health departments, combined with the decentralization of health in many provinces, has resulted in a fragmentation and dilution of specialized expertise that has made the health system vulnerable to unexpected new problems.

Lesson Five – Lack of Understanding About Vulnerable People

The Final Report describes the Red Cross's attempts to avoid offending two groups that had borne the brunt of the HIV/AIDS epidemic and who thus may have posed a special risk as blood donors. Having inadvertently offended Haitians and gays through early public statements, the Red Cross then bent over backwards to avoid giving further offence, with the result that information central to blood safety was both delayed and not sufficiently publicized.

Well-meaning attempts to reach the so-called "gay community" through individual contact with gay leaders by local public health workers displayed a critical lack of understanding of the communication target. In some places, effective partnerships between gay and public health organizations emerged. But in other locations, they did not. The chosen strategy reflected a lack of understanding that many men who have (or who have had) sex with men do not define themselves as gay, and many more who may well think of themselves as gay are not connected to the so-called gay community. The focus should have been on men who have sex with men, not on how these men defined or affiliated themselves.

Canada's health systems have usually been organized in such a way that senior thinkers and decision-makers are remote from service recipients. This is particularly problematic when considering the needs of those who often bear the brunt of emerging health problems, for example injection drug users, street people, the mentally ill, otherwise marginalized people and communities, and so on. The decentralized region-based health structures currently being implemented can help, but only if there are strong and reliable connections between those who possess "front line" information, and those who make system-wide decisions.

Lesson Six – Politics and Public Health Funding

The Final Report states that public health has been chronically underfunded, which contributed to the blood tragedy. I believe that public health has two characteristics that make its funding problematic.

First, public health is least visible when it is working best. In the competition for public dollars and political priority, what is not visible may receive little attention. Preventive or protective functions are noticed most when they fail – as with Canada's blood supply.

Public health is often in the position of justifying resource needs on the basis of problems successfully avoided, or of hypothetical future problems. Politicians rarely respond well to this kind of argument, particularly when faced with the public and professional pressure to put more money into the curative side of health. In many provinces public health is less visible than ever as regionalization has pushed its operating side away from where major policy and resource decisions are made.

Second, public health often has its highest political visibility when raising issues that politicians would just as soon avoid. Food and water safety, occupational and environmental health, alcohol and drugs, for example, provide many issues with significant political consequences that public health professionals champion, often in the face of pressure from those with a vested interest in the status quo. Politicians rarely warm to those they believe are causing political problems, even when they are public health professionals simply doing their jobs.

A concerted effort must be made to explain public health to the public, especially the preventive and protective functions that are seen only when they fail. At the same time, public health advocates must be careful not to generate a negative reaction in politicians and senior decision-makers by how they approach their responsibilities. Politicians do listen to those with an understanding of the irresolvable dilemmas of modern politics, and to those who have a track record of not crying wolf, unless there really is one!

Lesson Seven – Is Big Better?

The Final Report concludes that a large, national, unitary blood system is better than smaller, local and pluralistic ones. Canada is committed to uniform, national programs, so that all Canadians, everywhere and always, will receive the same benefits of citizenship. This essentially political value is supported by visions of large, smoothly running, private-sector organizations that are believed to exhibit economies of scale, as well as predictability and uniformity of outcome. In the health sector, this notion has led to the creation of "super hospitals" or large health authorities through the amalgamation or elimination of smaller entities in many provinces, and calls for new national pharmacare and home care programs.

The price that size exacts in terms of institutional inertia, loss of flexibility, and a lack of responsiveness to changing conditions has often been ignored. The extent to which economies of scale are offset by increased coordination costs also goes unrecognized. Many large private sector organizations, recognizing the inherent problems of size, have introduced small-scale operating units, local decision-making and competitive pluralism. There is growing awareness that the kind of executive skill necessary to make large organizations work well is probably rare, and unlikely to be widely available within a poorly paid and often demoralized public service. Politicians also seem increasingly likely to favor "closer to home" solutions to problems, and resist the creation of large-scale institutional responses. Thus, there has been rapid movement to regionalized health systems in many jurisdictions.

This rather schizophrenic posture, that simultaneously values large unitary systems and small local solutions, suggests a difficulty in distinguishing political values from practical considerations. As a result, far too much emphasis is placed on finding structural solutions to problems that may be based more in a lack of executive skill, planning capacity, and clarity of purpose.

Canada's blood system had tight central control of policy and procedure that forbaid innovation by local administrators attempting to respond to local conditions. At the same time, it exhibited an unwillingness to exercise central control so as to improve the transfer of blood and blood products from one province to another. The Final Report suggests that this action alone might have relieved some of the pressure that led the blood collection system to be so desperate to maintain its donor base.

A major challenge for health decision-makers is to resist the notion that problems can be solved solely through structural change or a resort to large organizations.

Non-governmental organizations are often thought to be more flexible and responsive to changing conditions, and thus more able to act quickly. Yet governments routinely impose on these agencies the same requirements, and sometimes methods, that make their own line operations less effective.

Lesson Eight – Ambivalence to Non-Government Organizations

Non-governmental organizations are often thought to be more flexible and responsive to changing conditions, and thus more able to act quickly. Yet governments routinely impose on these agencies the same requirements, and sometimes methods, that make their own line operations less effective. More troubling is that government sometimes imposes accountability standards that it will not apply to itself. The result is often a non-government agency that is less effective than it could be.

For example, the Canadian Blood Committee had complete control over the Red Cross's blood program budget. If the Red Cross made significant expenditures without prior approval, conflict occurred. The Red Cross was thus unwilling to make critical, but unanticipated, expenditures without approval, even if the funds already existed. Yet the Committee members had no deci-

The Krever Inquiry reveals a chronic lack of useful political, bureaucratic or professional leadership, combined with a willingness to allow vested interests (including national political goals) too much influence on decisions that ultimately affected the health of individual Canadians.

sion-making authority of their own, and thus could on their own only turn down, or delay, a decision. A positive decision depended on the slow approval processes at the members' many home Ministries, each with its own agenda and decision-making process.

If we believe that a non-governmental agency or, for example, an operating entity within a decentralized health system offers substantial advantage over direct government operations, we must resist the tendency to impose restrictions that remove that advantage.

Lesson Nine – Leadership and Reputation

Professionals tend to defer to the opinions of others thought to be knowledgeable about a particular issue, and not to question too closely. The Final Report shows how the Red Cross was repeatedly deferred to in its opinion that the blood supply was safe, and that the risk of HIV transmission by transfusion was minimal. Government agencies, regulators, and many professionals apparently agreed, even though a cursory examination of the factual basis for this opinion, given what was known at the time about HIV, should have raised serious questions. Example: the Red Cross estimate that the risk of HIV infection was about 1.5 in a million transfusions demonstrated a lack of even a rudimentary knowledge of statistics, and of long-latency diseases. Even if the estimate was correct, why did no one acknowledge the much greater risk from pooled blood and blood products that had already been demonstrated with hepatitis B?

The Krever Inquiry reveals a chronic lack of useful political, bureaucratic, or professional leadership, combined with a willingness to allow vested interests (including national political goals) too much influence on decisions that ultimately affected the health of individual Canadians.

The federal government and its federal/provincial coordinating mechanisms have been unable to exercise effective leadership on most national health issues. Where leadership has occurred, it has been a triumph of individuals over an unresponsive system. This is likely to continue, with leadership on critical health issues coming not from government agencies per se, but rather from among health professionals willing to take significant personal and career risks.

Conclusion

The Krever "story" left me with the belief that a disaster in Canada's blood system was probably inevitable, given the risks and the inadequate problem-solving approaches within the responsible organizational and bureaucratic systems. However, I don't think that the precise nature of the tragedy that did occur was predictable. HIV/AIDS was the specific triggering factor that played out within an increasingly dysfunctional system to create the blood tragedy.

The Krever Inquiry was not able to pursue matters into the political realm. However, the Final Report clearly demonstrates that many of the major mistakes of process and judgment were made by trained medical professionals rather than by non-physician career bureaucrats or politicians, even though these groups no doubt contributed in a significant way.

Another public health tragedy may now be underway.

Despite the general insights provided by the Krever Inquiry, I see no reason to conclude that another preventable public health tragedy is impossible. Time will tell if we have resolved those aspects of our blood system that created the specific opportunity for disaster detailed in the Final Report. But the same forces and ways of doing things that contributed to that tragedy are still deeply embedded in our public institutions, and in many of us.

Indeed, another public health tragedy may now be underway that illustrates many of the points discussed above. A marginalized community (in this case injection drug users) is experiencing an epidemic of death and disease resulting not from anything inherent in the drugs that they use, but more from the ineffective and dysfunctional methods that characterize our attempts to control illicit drugs and drug users. There is the same unwillingness to carefully analyze the problem or to depart from traditional methods and conventional thought that was integral to

I also suggest watching very carefully the regionalization experiments underway in some provinces. All of the factors that the Krever Inquiry uncovered would seem to exist in some of these.

the blood tragedy. There is a struggle for power and control over the issue between law enforcement and public health. There is a profound lack of understanding among decision-makers and many health professionals regarding the nature of the community and individuals at risk.

The hoped-for national political consensus and permission to act effectively on this public health issue is unlikely to come, despite awareness by local politicians and public health professionals of the seriousness of the problem. There is little possibility of effective national action, and yet national policy prohibits the kind of local initiative that might provide useful responses. Our committees meet, the media reports the political rhetoric and the disagreements of experts, and effective program responses remain in limbo as we try to sort out what are in essence power and control issues. Yet people continue to die in alarming numbers, and no one seems to notice or care very much.

I also suggest watching very carefully the regionalization experiments underway in some provinces. All of the factors that the Krever Inquiry uncovered would seem to exist in some of these. A potentially dangerous situation exists as a result of the lack of meaningful leadership, general confusion over budgets, authority and purpose, a lack of good operating information, fragmented or non-existent communications systems, political values overriding technical and scientific realities, the dominance of curative health over public health, overworked staff and underfunded agencies and regulators, and the often determined opposition of various vested interests. Simple structural change won't solve the problems regionalization is intended to remedy. Only consideration of all these other issues is likely to make a lasting difference.

It may not be possible to predict exactly where the next challenge will come from. The nature of our ever smaller and stressed world, combined with the ingenuity of biological and evolutionary processes, provide no reason for complacency. We must address what is dysfunctional in our organizations, professional approaches, and in ourselves, while avoiding wherever possible the divisive and ultimately meaningless issues of power and control that played such a large role in the blood tragedy.

The problems I've outlined above are partly structural, and there will be some structural solutions such as better reporting and communication systems, changes in legislation, and different organizational approaches. Yet the problems play out against a backdrop of human fallibility that is inevitably part of any human endeavor and must temper our expectations and enthusiasm for quick fixes. Such problems are rarely completely resolvable, and even partial solutions take time and determined effort.

The most heartening lesson in the Final Report is that individuals can and do make a difference. The consequences of the blood tragedy would likely have been even more serious without the actions of some individual professionals.

I challenge everyone to read some part of the Final Report concerned with the actions of key individuals and organizations, and seriously ask themselves: What would I have done? What personal action, knowledge, or skill might have resulted in a better outcome? How do I contribute to the dysfunctional aspects of the organization I'm now part of? How might my own professional and personal behavior contribute to a new public health disaster – or to its prevention?

– Jan Skirrow

Jan Skirrow was in the public service for 25 years. He held order-in-council appointments at the provincial and federal levels, including Deputy Minister of Community & Occupational Health in Alberta. He now works as a consultant for Diane McAmmond & Associates, Duncan, BC. Jan is a member of the Ministerial Council on HIV/AIDS. He can be reached at <dma@islandnet.com>.

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

PREGNANCY AND HIV/AIDS

HIV Testing and Pregnancy: Medical and Legal Parameters of the Policy Debate

In a paper written for Health Canada as part of the Joint Project on Legal and Ethical Issues Raised by HIV/AIDS of the Canadian HIV/AIDS Legal Network and the Canadian AIDS Society, Lori Stoltz and Louise Shap have provided the most compelling analysis yet of the medical and legal issues that should inform the policy debate regarding the HIV testing of pregnant women.[1] While focusing on Canadian law, the paper will be most useful to policy-makers worldwide. We reprint the paper's executive summary.

Introduction

There are now a broad range of medical interventions and approaches available to reduce the risk of perinatal HIV transmission: behavioural counselling intended to prevent women of childbearing years from contracting HIV in the first place; avoidance of pregnancy by women who are HIV-positive; termination of pregnancy; antiretroviral prophylaxis; avoidance of invasive obstetrical procedures during pregnancy and birth; caesarian section delivery; and avoidance of breastfeeding. Beyond primary prevention efforts, the effectiveness of these interventions depends upon the identification of women who are HIV-positive at a point in their pregnancies when such interventions might prove helpful.

At present, the serostatus of many HIV-positive pregnant women in Canada goes undetected and, as a result, they are left without advice, care, and treatment that would assist them in making choices to best promote their own health and that of their foetuses during pregnancy.

These facts underscore the need for a medically and legally appropriate policy for the HIV testing of pregnant women in Canada.

Object of the Paper

The object of the paper on *HIV Testing and Pregnancy: Medical and Legal Parameters of the Policy Debate* is to analyze the following questions with a view to informing that policy development:

- Should HIV testing be offered to all pregnant women, or only to those at increased risk of HIV infection?
- Should HIV testing of pregnant women be voluntary, or should it be mandatory?
- Should physicians be required to secure the informed consent of pregnant women before proceeding with HIV testing, or can this requirement be abrogated?
- Should the HIV testing of pregnant women be characterized as "routine"? and
- What added supports are necessary to ensure the effectiveness of provincial and territorial policies for the HIV testing of pregnant women in Canada?

Directly at issue in this debate is the extent to which the rights of an HIV-positive pregnant woman may be overridden – if at all – to protect the health of the foetus she carries. Central to the analysis of the preceding questions, therefore, is the need to confront the potential for conflict between maternal and foetal interests presented by the HIV testing of pregnant women and to strike a balance between them in accordance with the current state of Canadian law.

The paper reviews the current state of the law in the following areas as a starting point for its analysis:

- What is the nature and extent of an individual's right to exercise informed consent to proposed medical interventions?

- What information must be disclosed to meet informed consent requirements for proposed medical interventions in the "ordinary case"?
- Who is responsible for making decisions about medical interventions that may affect the health or life of the foetus, and what information must physicians provide to inform that decision-making process?
- Is a woman's right to refuse a medical intervention abrogated by pregnancy?
- What are the constitutional limits upon governmental initiatives regarding the HIV testing of pregnant women?
- What are the general principles and approaches that would govern application of the *Canadian Charter of Rights and Freedoms* in those circumstances? and
- What are the general duties of governments in policy-making?

Recommendations

The paper's analysis yields the following recommendations:

1. Provinces and territories should require that physicians offer HIV testing to all pregnant women.
2. Provinces and territories should require that physicians offer HIV testing:
    (1) as early in pregnancy as possible; and
    (2) where possible, to women considering pregnancy.
3. Provinces and territories should require that HIV testing of pregnant women be voluntary.
4. Provinces and territories should require that physicians obtain the voluntary and specific informed consent of pregnant women before proceeding with HIV testing. In particular, physicians must ensure that during pre-test counselling:
    (1) women are provided with sufficient information (which may include both written and oral information, and may involve health-care providers other than physicians) to understand the purposes, risks, harms and benefits of being tested or not tested, for them and for their foetuses;
    (2) the information provided meets generally applicable standards for informed consent to HIV testing; and
    (3) the information provided includes a fair and accurate summary of all interventions available to reduce the risk of perinatal HIV transmission, including, but not limited to, antiretroviral prophylaxis.
5. Provinces and territories should require that following receipt of HIV test results, physicians provide post-test counselling in accordance with generally applicable standards for HIV testing.
6. Provinces and territories should support the effectiveness of HIV testing policies for pregnant women with:
    (1) outreach to, and education of, physicians and other involved health-care providers to:
        (i) increase awareness of the availability and effectiveness of medical interventions to minimize the risk of perinatal HIV transmission; and
        (ii) ensure adherence to the prescribed HIV testing policy;
    (2) appropriate compensation to physicians and other involved health-care providers to support adherence to the prescribed HIV testing policy, including, in particular, the delivery of comprehensive pre-test counselling to fulfill informed-consent requirements;
    (3) outreach to, and education of, pregnant women to increase awareness of the availability of HIV testing and the availability and effectiveness of medical interventions to minimize the risk of perinatal HIV transmission;
    (4) access to appropriately specialized care and treatment to minimize the risk of perinatal HIV transmission for all pregnant women who test HIV-positive; and
    (5) evaluation of the policy's effectiveness at minimizing the number of perinatal HIV transmissions in Canada, and implementation of necessary changes.
7. Provinces and territories should not designate HIV testing of pregnant women as "routine." Use of the term "routine" in the phrase "routine counselling/voluntary testing" would be acceptable.
8. Provinces and territories should require physicians to ensure that during pre-test counselling, women are advised that HIV testing is recommended for all pregnant

> Provinces and territories should require that physicians obtain the voluntary and specific informed consent of pregnant women before proceeding with HIV testing.

women because:

- it is important for all pregnant women to know their HIV status so that, if positive, they can have access to the full range of appropriate care and treatment to benefit their own health and that of their foetus; and
- evidence indicates that women in Canada may be at risk of HIV infection without knowing it.

9. The licensing bodies for physicians should establish express standards of practice for the conduct of HIV testing for pregnant women and women considering pregnancy, and take all steps necessary to actively implement, monitor and enforce compliance with these standards.
10. Provinces and territories that wish to support their HIV testing policies with amendments to their laboratory requisition forms:
    (1) should avoid "default" testing (ie, amendments that would permit testing to proceed in the absence of a patient's express refusal to consent to testing); and
    (2) should carefully investigate and assess the effect of all other proposed amendments upon physician practices, to ensure that they effectively block improper test orders (ie, those ordered in the absence of patients' voluntary, specific and informed consent).
11. Provinces and territories should support HIV testing policies for pregnant women with strong measures:
    - to protect the right of pregnant women to exercise informed consent to HIV testing;
    - to protect the right of pregnant women to confidentiality in relation to their HIV test results; and
    - to combat the stigmatization and discriminatory treatment of all persons diagnosed as HIV-positive.
12. The federal government should fully interpret and fulfill its mandate under the *Food and Drugs Act* and regulations, engaging in the active regulation of all antiretroviral drugs used during pregnancy regardless whether their approved uses include reducing the risk of perinatal HIV transmission. In particular:
    (1) the HPB must take all necessary steps to continually assess the risks associated with the administration of those antiretroviral drugs used during pregnancy (for both women and the foetuses they carry), including the development and implementation of an active surveillance plan to monitor all adverse reactions;
    (2) further to (1), the HPB should integrate the Canadian Registry into the HPB's formal regulatory apparatus and expand its scope to include the mandatory reporting of all adverse reactions to antiretroviral drugs used during pregnancy, experienced over time by women and the foetuses they carry;
    (3) the HPB must determine whether the appropriate management of identified risks associated with the use of antiretroviral drugs during pregnancy requires regulatory action and, if so, take all necessary steps to that end, including the communication of the nature and extent of all risks associated with the administration of antiretroviral drugs during pregnancy; and
    (4) in order to facilitate the actions described in (1) and (2) above, the HPB must establish effective communication links with physicians prescribing antiretroviral drugs, the patients to whom they are administered, provincial/territorial and federal public health authorities, and regulatory authorities in other countries.
13. Federal, provincial and territorial governments should implement effective and sustained primary prevention measures to reduce the number of HIV-positive women and men in Canada.
14. Provincial and territorial governments should require that physicians:
    (1) offer HIV testing to men considering fathering a child on the basis of voluntary, specific and informed consent; and
    (2) counsel those men with HIV-positive test results to refer for counselling and HIV testing sexual partners who may be pregnant or considering pregnancy.

Copies of *HIV Testing and Pregnancy: Medical and Legal Parameters of the Policy Debate* can be obtained from the Canadian HIV/AIDS Clearinghouse (tel: 613 725-3434; email: aids/cpha@cpha.ca) or the Canadian HIV/AIDS Legal Network (tel: 514 397-6828 ext 227; email: enolet@aidslaw.ca). A summary of the document is also available on the Health Canada website at <www.hc-sc.gc.ca>.

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[1] L Stoltz, L Shap. *HIV Testing and Pregnancy: Medical and Legal Parameters of the Policy Debate*. Ottawa: Health Canada, 1999.

CRIMINAL JUSTICE

Criminal Law and HIV/AIDS: New Developments

Since the last issue of the Newsletter, there have been developments in several jurisdictions in the area of criminal law and HIV/AIDS. The Supreme Court of Canada's decision in September 1998 in *R* v *Cuerrier* is summarized elsewhere in this issue. This article notes the outcome in another recent Canadian case (in Newfoundland) involving unprotected sex without disclosure of HIV-positive status, and provides an update on an Ontario "biting" case reported in the last issue. It also reviews some developments in Australia, the United Kingdom, South Africa, the US, and other jurisdictions.

Canada

Charges laid in case of unprotected sex without disclosure of HIV-positive status

At a preliminary inquiry on 7 July 1998 in *R* v *Hollihan*,[1] the Newfoundland Provincial Court ruled that an accused charged with common nuisance for having unprotected sex with one woman without disclosing his HIV-positive status would be committed for trial. Section 180 of the *Criminal Code* provides that a person who does an "unlawful act or fails to discharge a legal duty and thereby endangers the lives, safety, health, property or comfort of the public" commits a *common nuisance,* which carries a penalty of up to two years' imprisonment. In the earlier Ontario case of *R* v *Ssenyonga*[2] the Ontario Court (Provincial Division) had held at a preliminary inquiry that the HIV-positive accused's unprotected sexual relationships with three specific complainants did not endanger the health of "the public." However, Hyslop J of the Provincial Court rejected this reasoning, saying:

> Specific individuals are members of the public and it matters not whether deliberate unprotected sex is had with one, one thousand, or one million members. Such acts endanger these people, and endanger anyone with whom they may subsequently become intimate, given the highly communicable nature of the virus. It follows that I am inclined to accept the definition of "public" followed in the dangerous driving cases.... [T]he insidious, transmittable, infectious aspect of this virus, where millions are affected, sets this apart from the ordinary. This infectious, contagious aspect of wilful, unprotected sex endangers, potentially, thousands of people, depending on the sexual appetite of the complainant.

> HIV/AIDS is first and foremost a public health issue and it is internationally accepted that non-coercive measures are the most successful means through which public health authorities can reduce the spread of the disease.

HIV-positive accused with mental disorder detained as "significant threat" to public

In January 1998, an Ontario trial court ruled in *R* v *Mitchell* that an HIV-positive woman had committed aggravated assault for biting a police officer, thereby "endangering her life." The court also found the accused not criminally responsible on account of mental disorder (expert testimony indicated a diagnosis of schizo-affective disorder and an underlying antisocial personality disorder), and noted that "it is questionable whether she knew the consequences of her biting action might be to transmit the HIV virus [sic]." In a subsequent disposition hearing, however, the judge ruled that the accused "does pose a significant threat to the safety of the public," and therefore ordered that she be detained in custody in a mental health facility.[3] This order is subject to future review.

In reaching this conclusion, the trial judge rejected the approach recently taken by the BC Court of Appeal in the case of *Chambers* v *BC (Attorney General)*, where that Court ruled that an HIV-positive sex worker "should not be detained under the *Criminal Code* because she is physically ill."[4] In *Chambers*, the Court ruled that a person could be detained under the *Criminal Code* only if the "significant threat" related to criminal conduct by the person to be detained, and did not extend to the risk of spreading a communicable disease.

In *Mitchell,* however, the trial judge disagreed, and ruled: "It is not the presence of the HIV virus [sic] in and of itself that causes the accused in this case and in the case, I would suggest, in *Chambers*, to be viewed as a significant threat, but rather, it is the overlaying factor of her mental condition which renders her at risk for spreading the HIV virus [sic]. Persons with HIV do not, in and of itself [sic], constitute a risk to the public. But a person with mental conditions such as I have found that the accused has in this case does present a significant threat to the safety of the community, even though it may not be criminal."[5] Although not specifically stating the conclusion, the trial judge's decision suggests that it is the possibility not just of a bite, but a bite by an HIV-positive person, that could pose a "significant threat" warranting the accused's detention in this case.

Appeal dismissed in case of HIV-positive sex worker imprisoned for biting police officer

As reported in the last issue of the *Newsletter,* in May 1996 an Ontario trial court sentenced an HIV-positive transgendered sex worker to imprisonment for two years less a day for "aggravated assault" for biting a police officer on the hand: *R* v *Thissen*.[6] In entering a guilty plea at this first stage, the "fact" that the bite "endangered" the officer's life was admitted. In a short decision released on 12 May 1998, the Ontario Court of Appeal upheld the sentence.[7]

On appeal, counsel sought leave to introduce further evidence regarding transmission via biting, in support of the argument that the facts do not support the charge of "endangering" the officer's life. However, the Court ruled that this evidence "would not be decisive in placing the risk of HIV infection below the level required by *R* v *Thornton*." (In *Thornton*,[8] an HIV-positive man was convicted of common nuisance for donating blood, because it was "reasonably foreseeable" that his conduct "could cause serious harm to other persons.") By implication, the Court has seemingly accepted that a bite "could" transmit HIV and may therefore be the basis for a charge of aggravated assault. The appellate court further upheld the three-year probation imposed (including the condition of not engaging in unprotected sex) as appropriate, "given the appellant's conduct in using her disease to endanger others."

Sentence upheld in case of HIV-positive rapist

In February 1998, in the case *R* v *Winn*,[9] the Ontario Court of Appeal dismissed the appeal against a sentence of 12 years' imprisonment by an HIV-positive man who pleaded guilty to a charge of aggravated assault. The accused had seriously beaten the victim and had ejaculated into her mouth, into an open facial wound caused by the beating, and into her vagina. The victim was not infected.[10] The prosecution and defence counsel jointly submitted that seven years' imprisonment was the appropriate sentence. The Court of Appeal ruled the trial judge was justified in departing from this in imposing the higher term of 12 years because the accused had a lengthy criminal record (including crimes of violence) and knew that he was HIV-positive.

Australia

On 2 December 1997 a trial court in Victoria sentenced Samuel Mutemeri to six months' imprisonment on 12 counts of reckless endangerment. He was alleged to have had unprotected sex with his former girlfriend. Pursuant to s 22 of the Victorian *Crimes Act* 1958, "a person who, without lawful excuse, recklessly engages in conduct which places or may place another person in danger of death is guilty of an indictable offence." An earlier appellate court decision defined recklessness as existing where "there is foresight on the part of an accused of the probable consequences of his actions and he displays indifference as to whether or not those consequences occur."[11]

On 29 April 1998 the Victorian Supreme Court overturned Mutemeri's conviction on these 12 counts, ruling that the magistrate had erred in finding beyond reasonable doubt, without hearing any evidence, that the accused's conduct exposed the complainant to an "appreciable risk" of death. Mandie J also questioned whether this criminal provision is applicable to cases of alleged exposure to the risk of HIV transmission: "I have some doubt as to whether the offence created by section 22 of the Crimes Act is properly to be construed as applicable to cases other than those where a person is exposed to the risk of a death of some immediacy or imminence."[12]

However, on 6 March 1998, a few weeks before this appeal decision in the Mutemeri case, a Victoria County Court convicted "F," an HIV-positive 52-year-old father of four with no previous convictions and described by the judge as a "closet bisexual," on similar charges for engaging in unprotected oral and anal sex with three men. Two of these men were subsequently diagnosed HIV-positive. In convicting "F" on 10 separate counts of reckless endangerment, the court imposed a sentence of eight years' imprisonment (with no eligibility for parole for five years). "F" attempted suicide by hanging in prison two days afterward, and died in hospital two weeks later from injuries inflicted during the attempt.[13]

In another case, an HIV-positive doctor in Victoria was charged under the same statute with six counts of reckless endangerment for engaging in unprotected sex on three occasions with his wife. Three charges relate to the woman; the other three charges allege he endangered their child's life at the moment of conception. According to some reports, the accused has maintained that he had disclosed his HIV-positive status to his wife. Neither his wife nor the daughter she gave birth to have tested HIV-positive.[14]

An HIV-positive man in Western Australia was ordered at the end of April 1998 to stand trial on charges of causing grievous bodily harm (as well as charges relating to indecent dealing with a minor), based on allegations that he transmitted HIV to a youth with whom he had a two-year casual sexual relationship.[15]

Finally, a Committee preparing a draft Model Criminal Code for enactment in all Australian jurisdictions issued its final report and draft code in 1998, after receiving submissions on its previous proposals. The Committee recommends that the national Code should include an offence of reckless endangerment for "conduct that may give rise to a danger of death or serious harm," which is defined as including "exposing a person to the risk of catching a disease that may give rise to a danger of death or serious harm." The proposed Code specifies that a "merely theoretical" danger of death or serious harm will not be sufficient for criminal liability, but that it is possible for conduct to give rise to such a danger "whatever the statistical or arithmetic calculation" of the degree of risk of death or serious harm involved.[16]

United Kingdom

Citing the longstanding decision in *R* v *Clarence*,[17] on 18 June 1996 a trial judge dismissed a charge of causing grievous bodily harm against a 25-year-old man alleged to have transmitted hepatitis B to his girlfriend through unprotected sex with her while she was pregnant. The judge expressed the view that Parliament ought to enact an offence of "reckless transmission of disease."[18]

In 1998 the UK government continued its review of the criminal law dealing with offences against the person, in preparation for introduction of new legislation. The Terrence Higgins Trust (THT), one of the country's largest AIDS service organisations, responded to the government's Consultation Paper and Draft Bill. THT submitted that while there was some justification for prosecuting those who purposefully transmit HIV to others, public health considerations militated against extending criminal liability any more broadly (including to reckless transmission of disease). THT highlighted its concerns about the potential detrimental effect of criminalization on public health efforts to prevent the spread of HIV.[19] Subsequent indications are that the government has rejected the Law Commission's proposal to criminalize minor illnesses and "reckless" transmission, and proposes to restrict prosecutions to cases where "it can be proved beyond reasonable doubt [that a person] had deliberately transmitted a disease intending to cause a serious illness."[20]

South Africa

The South African Law Commission has released for comment its discussion paper entitled The Need for a Statutory Offence Aimed at Harmful HIV-Related Behaviour. In an earlier working paper released in 1995, the Commission had reached the preliminary conclusion "that the criminal law is not pre-eminently the means by which to combat the spread of

HIV" and was therefore "not in favour of the creation of a statutory offence aimed specifically at HIV-related harmful behaviour. The main reason given for this was that conduct by persons with HIV which merits punishment remains punishable under the existing common law crimes."

In September 1998, press reports indicated a man had been charged with attempted murder in KwaZulu/Natal for allegedly having sex with two women without disclosing his HIV-positive status. According to the Commission, this is the first criminal prosecution of its kind in South Africa. As of the publication of the Commission's discussion paper, the case remained outstanding. Reports of such incidents of deliberate transmission led to public calls for the imposition of criminal sanctions and the Commission was asked by the Department of Justice "to investigate the need for legislation with regard to the criminalisation of acts by persons with HIV/AIDS who deliberately or negligently infect others, and the compulsory HIV testing of sexual offenders." It has chosen to address these issues in two separate discussion papers. In the recently released paper, the Commission confirms its 1995 conclusion that HIV/AIDS is

> first and foremost a public health issue and it is internationally accepted that non-coercive measures are the most successful means through which public health authorities can reduce the spread of the disease. However, it as accepted ... that there are individuals who, through their irresponsible and unacceptable behaviour, deliberately place others at risk of HIV infection. Where HIV-related behaviour results in harm to others (ie, exposure to or transmission of HIV), public health measures in themselves are insufficient and the criminal law undoubtedly has a role to play in protecting the community and punishing those who transgress.[21]

The Commission is currently soliciting further comment on how, and in what form, the criminal law should play a role with respect to HIV-related harmful behaviour before reaching any conclusion on whether to recommend the creation of a statutory offence.

United States

Alaska

In June 1998 the state governor vetoed a bill approved by the state legislature that would have made it a felony to knowingly spread HIV by selling tainted blood or have sex without disclosing seropositivity. The governor noted that current laws against assault and reckless endangerment were adequate.[22]

Arizona

In early 1998 a bill was introduced in the state legislature to make knowingly exposing someone to HIV (though oral, anal, or vaginal sex or by sharing needles) a felony.[23]

Arkansas

In December 1998 prosecutors decided not to lay charges of exposing another to HIV against a man already charged with robbery. The accused was alleged to have bitten a man on the neck during the robbery, breaking the skin. Prosecutors said Arkansas law requires that the exposure occur through sexual contact.[24] The state Supreme Court also upheld the conviction of a 24-year-old man sentenced to the maximum of 30 years in prison for infecting a woman through unprotected sex without disclosing his status.[25]

California

In September 1998 the state legislature enacted a statute making it a criminal offence to willfully expose another person to HIV through sexual activity.[26] In December 1997, the Court of Appeal found that an HIV-positive person who engages in unprotected sex may commit aggravated assault if the act is likely to cause great bodily injury to their partner. However, citing medical journal articles, the Court also ruled that there was no evidence in the case before it that a single incident of unprotected sex between an HIV-positive man and an HIV-negative woman was "likely" to result in transmission.[27]

Georgia

In March 1998 a married US Army solider pleaded guilty at his court-martial to charges including aggravated assault, adultery, sodomy, and willfully disobeying an order for having unprotected sex with seven women without disclosing his HIV-positive status.[28]

Iowa

A sentence of 25 years' imprisonment was imposed in January 1999 on the first Iowan charged with criminally transmitting HIV. Charged in October 1998, he pleaded guilty to the allegation of engaging in oral and anal sex with a youth (who was not infected). The statute does not require actual transmission of the virus to establish the offence.[29] In October 1998 another man was charged with criminal transmission for failing to tell a woman of his status before having sex.[30]

Louisiana

In February 1999 a doctor convicted of attempted second-degree murder for injecting his lover with HIV-contaminated blood after she told him their 10-year relationship was over, was sentenced to 50 years' imprisonment with hard labour.[31]

Mississippi

In September 1998 an HIV-positive man was convicted by a jury and sentenced to the maximum term of five years' imprisonment for breaching a health department order requiring him to use condoms and spermicide when having sex and to inform his sexual partners of his condition.[32]

Missouri

In January 1999 medical technician Brian Stewart was convicted of first-degree assault and sentenced to life in prison for injecting his 11-month-old son with HIV-contaminated blood to avoid paying child-support payments.[33]

Nevada

The director of an AIDS program was sentenced to two-to-six years' imprisonment on the charge of attempted intentional transmission of HIV, after engaging in unprotected sex with two women without disclosing his HIV status. Neither complainant had tested positive at the time of sentencing.[34]

New Hampshire

In the first case of its kind in New Hampshire, a 27-year-old man was charged in 1998 with three counts of *reckless conduct* for allegedly having unprotected sex with a 14-year-old girl without disclosing his status. The teenager was not infected. New Hampshire does not have a law specifically making it an offence for an HIV-positive person to knowingly expose another to the virus.[35]

> An Ohio judge ordered an HIV-positive cross-dressing male prostitute to appear on two television stations to inform any of his past contacts of his status.

New York

In October 1997 public health officials in Chatauqua County announced that Nushawn Williams admitted having unprotected sex with dozens of teenage women without disclosing his HIV-positive status. He was subsequently charged with attempted second-degree assault and first-degree reckless endangerment, and a guilty plea was entered with respect to at least some of these charges at the end of February 1999.[36] Largely in response to the Williams case, a bill has been introduced in the state legislature to criminalize HIV transmission/exposure. The bill creates the new offence of "aggravated reckless endangerment," a felony punishable by up to 15 years in prison. The offence is committed when a person who knows that they are HIV-positive does not inform a sexual or needle-sharing partner of this. The bill applies to "sexual intercourse" or "deviate sexual intercourse" (defined as sexual conduct between unmarried persons and including anal sex, and also oral sex performed on either a man or woman), or even simply "offering" or "agreeing" to engage in such conduct in return for a fee (regardless of whether any sex actually takes place).[37]

Ohio

A new bill was introduced early in 1999 in the Ohio state legislature that would make it a felony offence for an HIV-positive person to have sexual relations without first disclosing their HIV-positive status, punishable with two to eight years in prison and a maximum fine of $15,000. The same bill passed the state House of Representatives in the fall of 1998 (by a vote of 93-1), but failed in the state Senate.[38] In November 1998, an Ohio judge ordered an HIV-positive cross-dressing male prostitute to appear on two television stations to inform any of his past contacts of his status, ostensibly in order to "protect the public's safety." Charged for attempted soliciting with the knowledge of his HIV status, the sex worker had disclosed to only some of his clients in the six months following his diagnosis. The other term of his plea bargain was 18 months' imprisonment. The ACLU condemned the order as "sending the wrong public health message" and as setting a dangerous example for other judges.[39] And in 1998 the Ohio Supreme Court upheld the felony conviction of an HIV-positive man who pleaded no contest to the charge of assault with a deadly weapon for spitting in the face of a police officer, and was sentenced to three to 15 years in prison. On appeal, he unsuccessfully sought to overturn his conviction based on the lack of medical evidence proving the possibility of HIV transmission via saliva.[40]

Tennessee

A man was charged in November 1998 with criminally exposing two women to HIV, although other women have reportedly filed similar complaints with police since his arrest. According to investigators, the accused told police he slept with several women over a year while aware of his HIV-positive status, and that he continued having sex because he was angry at being infected.[41] An HIV-positive woman was charged with two counts of criminal exposure to HIV, carrying a possible penalty of up to 12 years in prison, for having sex with two partners. She maintains that she disclosed her HIV status.[42]

Virginia

In 1998 the Virginia Court of Appeals upheld the conviction of a shoplifter for *malicious wounding* for biting two retail employees after telling them he had AIDS.[43] Two bills were before the legislature in January 1999. One creates the offence of "infected sexual battery," which would exist where a person aware of their HIV-positive status has sex without first disclosing this fact to their partner. The other would increase the penalty for engaging in prostitution if the HIV-positive sex worker has "the intent to transmit the virus."[44]

Wisconsin

A Milwaukee man pleaded guilty in January 1999 to the offence of first-degree recklessly endangering safety for having unprotected sex with a woman without disclosing his HIV-positive status. He was scheduled to be sentenced in March 1999 for up to five years in prison.[45]

Military justice system

An Army private pleaded guilty in January 1999 to aggravated assault for having unprotected sex without disclosing her HIV-positive status, and to the offence of disobeying a superior officer (who had ordered her to use a condom and tell sexual partners of her status). She was alleged to have had sex with eight men; she did not tell any of them about her HIV status, and had unprotected sex with three of them. She did disclose to a ninth man, but did not require him to wear a condom.[46] In November 1998 the US Supreme Court announced it will review a decision by the military's high court that bars the Air Force from dropping a major from its rolls after his conviction for disobeying a superior officer's order to practise only safe sex and disclose his condition to any sexual partner. Dropping his name from the rolls would cost him his veteran's benefit (including HIV medication). The Court of Appeals for the Armed Forces declared such an action to be unconstitutional "double jeopardy"; as he had already been sentenced to six years' confinement and a pay loss, the additional penalty would constitute a second punishment for the same offence. The US Supreme Court is expected to hear the appeal in the spring of 1999.[47]

Other Jurisdictions

France's highest court, the Cour de Cassation, ruled on 2 July 1998 that knowingly transmitting HIV was not tantamount to poisoning, finding that a man who infected his female companion with HIV while knowing he was seropositive could not be tried for poisoning, a charge equivalent to wilful murder.[48] In *Finland*, a 35-year-old US rap artist was charged with *attempted manslaughter* for engaging in unprotected sex without disclosing his HIV-positive status, allegedly with over a hundred women; he was sentenced in July 1997 to 14 years in prison and ordered to pay damages of between $63,000 and $73,000 to each of five women he infected.[49] In *Switzerland,* a man was sentenced on 9 November 1998 to three years' imprisonment for causing serious bodily harm by transmitting HIV to his girlfriend, to whom he had not disclosed his HIV-positive status. The prosecution sought a 10-year jail term, but defence counsel successfully argued that he had not acted with intent to kill.[50] Legislators in the *Philippines* passed national HIV/AIDS legislation at the end of June 1998 that imposes penalties on HIV-positive people who deliberately infect others; the act also establishes a national educational program and rights protections for HIV-positive people.[51] In *Costa Rica*, a bill was introduced in the Senate in 1996 imposing prison terms of three to eight years for people who do not inform their sexual partners of their HIV status, with penalties increasing if transmission actually occurred.[52]

– Richard Elliott

Richard Elliott is Director, Policy & Research, of the Canadian HIV/AIDS Legal Network. He can be reached at <relliott@netrover.com>.

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HIV/AIDS IN PRISONS

HIV and Hep C Seroprevalence and Associated Risk Behaviours in a Canadian Prison

In late fall 1997 a prisoner who had been sharing injection equipment with fellow inmates at Joyceville Penitentiary, a medium-security federal prison for men in Kingston, revealed that he was HIV-positive. This caused understandable concern among the apparently large number of prisoners who had shared injection equipment with the HIV-positive inmate. The prisoners were reluctant to seek HIV testing from the prison's health-care staff for fear of self-identifying as injection drug users, and of potential breaches of confidentiality. The prison's inmate committee therefore requested that an HIV-seroprevalence study be carried out in Joyceville as a way of providing inmates with access to anonymous testing. This article presents the results of the study, which showed that risk behaviours and rates of infection in the prison had increased substantially since a previous study had been undertaken at the same prison in 1995.

The Study

The Queen's University Study Group, which had previously carried out HIV and hepatitis C seroprevalence studies in both Joyceville Penitentiary and in Kingston Prison for Women,[1] and was still involved in risk-reduction education, was approached. After negotiations with Correctional Services Canada, the Study Group agreed to undertake an anonymous HIV and hepatitis seroprevalence study. Ethics approval was obtained from Queen's University Faculty of Medicine Ethics Committee, and in early March 1998 the study was carried out.

The study was carried out in a manner similar to the previous ones. An intensive pre-study education session was undertaken with the assistance of the Prisoners with HIV/AIDS Support Action Network (PASAN) and the Kingston AIDS Project (KAP). Prisoners volunteering a blood sample were given a numbered ticket, and the same number was put on the blood tube. Individual results were placed in an envelope with the tube number on the outside, and prisoners were able to obtain their own result in complete confidence. Post-test counselling was available from members of the study group, PASAN, and KAP. One important difference from the previous studies was the use of a risk behaviour questionnaire on drug use and tattooing. Each questionnaire, when completed by the prisoner, had the same number attached as was on the blood tube, and risk behaviour could therefore be linked to the blood result.

Study Results

355 of 520 prisoners (68 percent) volunteered a blood sample and 350 of 355 filled out questionnaires. 33 percent were hepatitis C–positive compared with 27.9 percent in the same prison in 1995, and 1.7 percent were HIV-positive compared with 1.0 percent in 1995.

No Risk Factors

27.1 percent reported no risk factors. Of these, 6.3 percent were hepatitis C–positive.

Tattooing (No Reported Drug Use)

57 percent had been tattooed both inside and outside prison, and of these 34.2 percent were hepatitis C–positive. 10.9 percent reported being tattooed outside prison only, and of these 15.8 percent were hepatitis C–positive. 11.1 percent had been tattooed inside prison only, and of these 5.1 percent were hepatitis C–positive.

> Injection drug use in the prison has doubled from 12 percent in 1995 to over 24 percent in 1998.

Injection Drug Use

24.3 percent reported using injection drugs in prison, compared with 12 percent in 1995. 64 people (18.3 percent) reported injection drug use inside and outside prison; of these, 85.9 percent were hepatitis C–positive. 46 people (13.1 percent) reported injection drug use outside prison but not inside; of these, 63 percent were hepatitis C–positive. 21 people (6 percent) reported injection drug use inside prison but not outside; of these, 52.4 percent were hepatitis C–positive.

Sharing Injection Equipment

11.4 percent reported sharing injection equipment inside and outside prison; of these, 90 percent were hepatitis C-positive. 6.6 percent reported sharing outside but not inside; of these, 73.3 percent were hepatitis C–positive. 7.7 percent reported sharing inside but not outside; of these, 66.7 percent were hepatitis C–positive.

HIV-Positive Individuals

Six individuals (1.7 percent) were HIV-positive. Five of them had used injection drugs at some time.

Conclusions

68 percent of inmates participated in the study after intensive education about the study had been undertaken and after the inmates themselves had requested a study. This response rate is very similar to the response rate for the previous study in the same prison in 1995, although in this second study a linked questionnaire was used.

Hepatitis C prevalence rose from 27.9 percent in 1995 to 33 percent in 1998, and the HIV rate from 1 percent to 1.7 percent. Injection drug use has doubled. It appears that the highest-risk individuals outside prison – those who inject drugs and share equipment – bring these habits into the prison. There is a worryingly high rate of hepatitis C in those who injected in prison only. Similarly, there is a high rate of hepatitis C infection in those who have shared only in prison. Moreover, it was in this group that we saw individuals with equivocal test results who were likely in the process of seroconverting. Since the study was completed we have become aware of one individual, negative for HIV in March 1998, who is now positive, and one individual who has contracted hepatitis C: both are injection drug users.

SPECIFIC DRUGS

DRUG	# REPORTING	% HEPATITIS C–POSITIVE
Heroin	80	77.6
Cocaine	20	87.0
Speed	12	83.3

> This prison is a public health disaster in process.

The low rate of hepatitis C in those tattooed inside prison and who had no injection drug use history may reflect the intensive education program on tattooing in Joyceville, which included making an educational film about the risks of tattooing that incorporated many of the prison's regular tattoo artists.

We could not demonstrate any protective effect of bleach among injection drug users.

Although the rate of HIV is still relatively low at 1.7 percent, this is many times that found in the general population, and given the fact that hepatitis C positivity is a marker for risk behaviour, this prison is a public health disaster in process. There is no reason to suppose that this prison is worse than any other in the system.

We urgently need to study another medium-security system to determine whether the low rate of infection with hepatitis C in those tattooed in prison is peculiar to Joyceville. If it is, we have clearly developed an effective education tool that needs to be applied elsewhere.

This study clearly shows an enormous burden of illness in this institution, in the form of hepatitis C. Many of the men are going to suffer years of ill health and many will die as a consequence. The cost of treatment both in and out of prison is going to be high both in terms of

There is no good evidence to suggest that strong bleach works, let alone solutions that can be drunk with impunity.

antiviral therapy and in the management of long-term illness in those who either do not respond to antiviral therapy or do not receive it. The public health implications are also alarming in that hepatitis C is not only spread through injection drug use and tattooing, but can be spread sexually.

Risk behaviour that transmits hepatitis C can also transmit HIV. The prevalence of HIV in street injection drug users across Canada is rapidly rising and the introduction of HIV-positive individuals with established high-risk behaviour patterns into the prison environment is going to lead to a rapid increase in HIV seroprevalence.

There are no easy solutions, and it is clear that many people arrive in prison already hepatitis C– or HIV-positive and bring with them their high-risk behaviours. We do need to implement some obvious measures without delay. These would include the following:

- Stop random testing for tetrahydrocannabinol (THC). The long period over which THC can be detected in the urine, as compared with cocaine or heroin metabolites, makes use of THC-containing preparations risky and, in our experience talking to a large number of prisoners, has pushed users toward use of hard drugs. The rather dramatic rise in the percentage of injectors in prison over the last three years lends some support to this idea.
- Make methadone maintenance accessible for all heroin users entering prison, not just those who have been given methadone outside prison. Methadone given in adequate dosage can be viewed not just as treatment but as a harm-reduction strategy. This should be done immediately, without the usual two- to three-year delay for a pilot scheme. This program will be expensive, but the cost of not implementing such a program will be much more expensive.
- Introduce effective drug rehabilitation programs. People who are dependent on drugs have an illness, and we need to recognize that fact just as we have come to accept that alcoholism is an illness, and to provide treatment rather than criminalization and persecution.
- Introduce needle exchange programs. These are working in European prisons. They are not the entire solution but they would help. Again, such schemes should be widely introduced at once, without the need for expensive pilot schemes, which have already been carried out in Europe. Provision of clean needles and syringes would reduce the risks to guards doing searches.
- Undertake intensive education programs with peer involvement to prevent prisoners starting injection drug use.
- Stop pretending that weak bleach solutions are the answer to anything. There is no good evidence to suggest that strong bleach works, let alone solutions that can be drunk with impunity. The provision of bleach to a large number of individuals using a small number of syringes in a clandestine and hurried fashion should not be used as an example of an effective harm-reduction strategy and a justification for not doing anything else.

Finally, the problems surrounding hepatitis C and HIV in prisons are a nexus of broader societal problems relating mainly to injection drug use and are a warning (if any were needed) that ultimately society is going to have to address them. From the perspective of the prison system, diminishing the number of drug-dependent people who are given custodial sentences would be of help.

– Peter M Ford & the Queen's University HIV Study Group

Dr Peter Ford is director of the HIV/AIDS Clinic at Kingston General Hospital and a member of the Department of Medicine, Queen's University at Kingston, Ontario. The members of the Queen's University HIV Study Group are PM Ford, M Pearson, D Bell, T Stevenson, J Austen, and P Sankar. Dr Ford can be reached at <fordp@post.queensu.ca>.

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[1] PM Ford et al. Seroprevalence of Hepatitis C in a Canadian Federal Penitentiary for Women. *Canada Communicable Disease Report* 1995; 21(14): 132-134; M Pearson et al. Voluntary Screening for Hepatitis C in a Canadian Federal Penitentiary for Men. *Canada Communicable Disease Report* 1995; 21(14): 134-136; PM Ford et al. Seroprevalence in a Male Medium Security Penitentiary - Ontario. *Canada Communicable Disease Report* 1994; 20(6): 45-47.

Male-to-Female Transsexuals and Transgendered People in Prisons: HIV/AIDS Issues and Strategies

Transsexuals and transgendered people in prison, including those with HIV/AIDS, share the needs of all prisoners for HIV/AIDS care and prevention services, but also have needs that are unique to that population. In this article, Ann V Scott and Rick Lines of the Prisoners' HIV/AIDS Support Action Network (PASAN) provide an overview of the major issues and recommendations contained in *HIV/AIDS in the Male-to-Female Transsexual and Transgendered Prison Population: A Comprehensive Strategy*, a brief prepared by PASAN.[1] The article first describes the research undertaken to produce the brief. It then provides some background information on transsexual and transgendered people in general and transsexual and transgendered youth and sex-trade workers in particular. The article discusses the risk of HIV infection for transsexual and transgendered prisoners. Finally, it summarizes the major issues confronting male-to-female transsexual and transgendered prisoners and makes recommendations for action in the following areas: prevention of HIV transmission; injection drug use and HIV; medical and support services; human rights and confidentiality; and aftercare.

Introduction

PASAN first began research into the HIV/AIDS service needs of male-to-female transsexual and transgendered prisoners in 1996. Since 1993, PASAN has been working with over 200 HIV-positive prisoners from across Canada. Approximately 10 percent of PASAN's HIV-positive clients identify as transsexual or transgendered. This number greatly overrepresents the proportion of transsexual and transgendered prisoners in any given prison population. PASAN believes that this overrepresentation of HIV infection in the male-to-female transsexual and transgendered prison population, combined with the unique needs of this population, demand attention from both the provincial and federal levels of correctional services.

PASAN's experience working with male-to-female transsexual and transgendered prisoners has led us to document many specific barriers faced by transsexual and transgendered prisoners with HIV/AIDS in trying to access proper health care and other support services. To document the issues and to identify solutions, PASAN prepared *HIV/AIDS in the Male-to-Female Transsexual and Transgendered Prison Population: A Comprehensive Strategy*. The document details 44 recommendations in the areas of prevention, injection drug use, medical and support services for people with HIV/AIDS, human rights, compassionate release, and confidentiality, testing, and aftercare.

> We have to ask for condoms, but most people don't. It's not safe to do so.
> *- Transgendered prisoner*

Fifteen male-to-female transsexual and transgendered prisoners and ex-prisoners living with HIV/AIDS were interviewed and used as consultants in preparing the document. Their experiences were expressed both through anonymous written questionnaires and through personal interviews.

The recommendations are based primarily on the experiences of male-to-female transsexual and transgendered people in federal and provincial prisons and jails in Ontario. Nevertheless, we believe the recommendations are relevant for the Canadian prison system as a whole (particularly in the case of federal institutions), although we are also aware that differing correctional, health-care, and human rights legislation from province to province may affect whether and how specific recommendations need to be implemented in provincial institutions.

Background

Who are transsexual and transgendered persons?

"Transgender" is an umbrella term used to describe those who live outside of normative sex and gender relations.[2] These are people who identify with a core gender identity that society believes is not congruent

> Rapes occur at night, no condoms used. Sometimes I can prevent rape by telling the person that I have HIV and that it could be passed on to them.
> *– Male-to-female transsexual and transgendered prisoner*

with their external genitalia. Six of the groups within the transgendered community are transsexuals, transgendered people, intersexed people, cross-dressers, drag kings and queens, and transvestites.

Transsexual and transgendered youth, prostitution, and HIV/AIDS

The transsexual and transgendered street youth community is a closely knit circle, where young prostitutes are often supported in the sex trade by older, more experienced prostitutes, who refer to the youth as their "daughters." These older sex-trade workers not only provide support and protection to these youth, but also help them learn their way around an often dangerous profession. Many of the transsexual and transgendered youth working on the streets are youth of colour who have faced further disenfranchisement and societal barriers resulting from institutionalized racism.[3]

The youth working the streets are often at great risk of violence, and they often live in a street subculture marked by drug use (both injection and non-injection) and unsafe sex. This living environment often places the youth at increased risk of HIV infection. Sex-trade workers have revealed that unsafe sex practices occur frequently, particularly among individuals working the streets. The use of alcohol or drugs, as well as financial incentives (more money for unsafe sex), leads to a high risk of HIV/AIDS infection in the transsexual and transgendered sex-trade community.[4]

Of 43 transsexual and transgendered youth surveyed by the Toronto-based Street Outreach Services, 35 were living with HIV/AIDS. Of these, 19 believed they were infected by a husband (a consistent partner in their life, and their protector) or boyfriend.[5] While this rate of seroprevalence should in no way be extrapolated to apply to transsexual and transgendered sex-trade workers as a whole, it is nevertheless indicative of the conditions of vulnerability in which many transsexual and transgendered prostitutes live and work.

The discrimination and violence experienced by transsexual and transgendered sex-trade workers are related to the denigration of prostitutes in Canadian society. Because of criminal prohibitions against soliciting, many sex-trade workers (male, female, and transsexual and transgendered) are forced to take their business practices underground. They work in dark parking lots, stairwells, and other remote areas where they can stay away from the eyes of police. Unfortunately, these types of work environments also make prostitutes physically vulnerable, placing them at increased risk of violence and death. Discriminatory attitudes and legislation against sex-trade work are at the root of this problem; they contribute not only to producing unsafe working conditions for transsexual and transgendered prostitutes, but also to creating social conditions where the risks of HIV infection are increased.

Because both drug use and communicating for the purposes of prostitution are penalized under the *Criminal Code*, many of the transsexual and transgendered youth will come into conflict with the law and may end up spending time in prison. Inequitable treatment of transsexual and transgendered sex-trade workers before the courts may come into play, thereby increasing their likelihood of incarceration. Anecdotal testimony received in preparation of the brief – from both transsexual and transgendered sex-trade workers and agencies serving the transsexual and transgendered community – suggests a pattern of differential, more punitive, responses to transsexual and transgendered individuals at trial. A 1998 study in Québec revealed that 50 percent of the transsexual and transgendered sex-trade workers interviewed had done time in jail.[6]

Risk for HIV/AIDS among transsexual and transgendered prisoners

The discrimination, inequality, health and safety issues faced by transsexual and transgendered prisoners are proportionate to the issues faced by transsexual and transgendered people in the community. Canadian prisons incarcerate both gay men and men who identify as "straight" but who engage in same-sex activities while inside. Male-to-female transsexual and transgendered prisoners who have not undergone sex-reassignment surgery and had their gender change legally registered are housed in male prisons, and are among the most marginalized and disadvantaged in the prison community. They are often used as sex objects and are

> Our health-care needs are not getting met. If I insist, I will get thrown into the hole. We must know how to play the game to get our health-care needs met. We need to know how to manipulate the system.
> – *Transgendered prisoner*

therefore at increased risk of violence within the institution. Many transsexual and transgendered prisoners find it necessary to trade sex for protection. Their very survival, therefore, hinges on their willingness to provide sex for their partners, who are often very abusive to them.

Issues and Recommendations

Prevention of HIV transmission

HIV is transmitted in prisons through unsafe needle use (sharing needles for injection drug use, tattooing, or body piecing) and unsafe sex. Male-to-female transsexual and transgendered prisoners are engaging in these activities and putting themselves at risk for HIV infection because they do not know that these activities are unsafe, do not know how to engage in them safely, or are denied access to the materials necessary to prevent HIV transmission.

Comprehensive education and responsive, gender-positive programs are the first steps in preventing HIV infection in the male-to-female transsexual and transgendered prison population. Comprehensive educational sessions for medical staff should be implemented that address the unique medical issues of male-to-female transsexual and transgendered prisoners. They should address issues such as hormones and their effect on overall health; the regular monitoring of hormones; and drug interactions between hormones, street drugs, and HIV/AIDS medications.

Educational services must also be provided to prison social workers and case management officers to assist them in developing skills to serve the unique needs of male-to-female transsexual and transgendered prisoners while incarcerated, for example, helping to ensure that all requirements and documentation necessary for sex-reassignment surgery are being met in the prison system.

To address these issues, we recommend:

1. External, community-based AIDS and health organizations should lead educational sessions. Peer education should also be promoted. Federal and provincial correctional services should recognize and utilize the expertise of community-based gender-positive agencies when planning any male-to-female transsexual and transgendered HIV/AIDS programs.
2. Condoms, dental dams, latex gloves, appropriate lubricants, and other safer-sex materials must be made available to male-to-female transsexual and transgendered prisoners in a discreet, non-identifying manner. Condoms prevent the sexual transmission of HIV/AIDS. Lubrication is essential for male-to-female transsexual and transgendered prisoners due to their risk of tissue damage during intercourse, which may cause bleeding and place male-to-female transsexual and transgendered individuals at increased risk for HIV/AIDS transmission. Condoms and other safer-sex materials must be distributed in such a way as not to stigmatize those individuals seeking access to them.

> Why be concerned about my health if I can't get my hormones? Identity is fundamental. The male-to-female transsexual and transgendered prison population's needs are not being considered by medical staff. They assume that our lifestyle is a choice, but it isn't.
> – *Transgendered ex-prisoner*

3. Known sexual offenders and sexual predators must not be segregated in the same protective custody units where male-to-female transsexual and transgendered prisoners are housed. Male-to-female transsexual and transgendered prisoners are vulnerable to sexual assault. Sexual predators should be identified and segregated from the general population, but not placed in the same protective custody units where male-to-female transsexual and transgendered prisoners are located.

Injection drug use and HIV

The link between drug use and transmission of HIV can be direct (through injecting with contaminated needles) or indirect (when impaired judgment leads to unplanned or unprotected sexual intercourse). PASAN has therefore advocated a multifaceted approach to dealing with drug use and the risk of HIV infection. This approach should include a needle exchange program, bleach-kit distribution, education on safer injection drug use and hormone injection, and drug treatment options – including methadone maintenance – for prisoners wishing to access them.

Among male-to-female transsexual and transgendered prisoners, syringes are shared not only for injecting narcotics but also for injecting hormones, thus placing these individuals at additional risk of HIV infection.[7]

To address these issues, we recommend:

1. A confidential needle exchange program should be implemented. Because the syringes needed for the proper injection of hormones are intramuscular, corrections services must also ensure access to intramuscular syringes.

Medical and support services

While incarcerated, transsexual and transgendered prisoners have access to a health-care system that many of them described as indifferent, or sometimes even hostile, to their unique needs. To provide this population with appropriate health care, it is necessary to consider and address the specific barriers transsexual and transgendered prisoners face when trying to access optimal health care. Correctional health-care providers must be given the resources and training to enable them to support the unique medical, hormonal, and psychosocial needs of transsexual and transgendered prisoners.

Universal access to health care is a fundamental right of all Canadians. Corrections services, at both federal and provincial levels, are mandated to provide a quality of care comparable to that available in the community. Given the unique medical needs of transsexual and transgendered prisoners with HIV/AIDS – whether in terms of HIV treatments or hormone therapy – it is very important that medical staff be knowledgeable in these areas.

To address these issues, we recommend:

1. Hormones should be given to all male-to-female transsexual and transgendered prisoners who have used them in the community, regardless of HIV status. Hormone access should not be contingent solely upon the approval of gender-identity clinics (such as the one at the Clarke Institute of Psychiatry in Ontario) or specific doctors approved by these clinics. Hormone usage should be monitored closely by health professionals who understand the effects of hormones on the endocrinological system.
2. All transsexual and transgendered prisoners with HIV/AIDS should have access to alternative therapies and non-approved treatments. Careful attention must be given to evaluating the degree to which the clinical drugs (for HIV/AIDS) and biochemical drugs (for hormone replacement therapy) interact and affect the progression of HIV/AIDS.
3. Transsexual and transgendered prisoners living with HIV/AIDS must be guaranteed access to medical and dental workers of their choice. In particular, they must have access to experienced and expert HIV primary-care physicians and endocrinologists who are gender-positive and aware of the health-care needs of transsexuals and transgendered people. They should also be able to access the psychiatric or psychological services of a clinician who is an expert in dealing with the transsexual and transgendered experience.
4. The services of community-based workers serving the transsexual and transgendered community or people with HIV/AIDS must be made available to all male-to-female transsexual and transgendered prisoners who desire them.

Human rights and confidentiality

Unfortunately, discrimination against people with HIV/AIDS is a fact of life in Canada. This is true in our society and it is true in the prison system. In Canadian prisons, societal AIDSphobia is often exacerbated by anti-prisoner and anti-drug user prejudices, as well as racism, sexism, transphobia, and homophobia. Transsexual or transgendered prisoners with HIV/AIDS often find themselves even further marginalized by virtue of their gender. In this atmosphere, anti-discrimination laws and human rights protections become even more crucial.

Transsexual and transgendered prisoners are subjected to unwarranted isolation and segregation. The reasons given for the punishment of isolation vary, but they share a common theme: the prisoner somehow jeopardizes the "good order of the institution," either because of HIV infection or because assumptions about the transsexual and transgendered prisoner's behaviour (when coupled with the knowledge that s/he is HIV-positive) is deemed to be a threat to either staff or other prisoners.

To address these issues, we recommend:

1. The confidentiality of male-to-female transsexual and transgendered prisoners' HIV status must be respected. Staff members who break the confidentiality of male-to-female transsexual and transgendered prisoners should be disciplined and/or dismissed. The distribution of medications, special diets, and nutrient drinks should not require a breach of confidentiality of transsexual and transgendered prisoners with HIV/AIDS. Transsexual and transgendered prisoners who want access to supportive counseling, medical treatment, and hormones must be guaranteed that their confidentiality will be respected.
2. No male staff should have the right to search female transsexual and transgendered prisoners; only female staff should be allowed to do searches.
3. Male-to-female transsexual and transgendered prisoners living with HIV/AIDS should not be involuntarily isolated or segregated. Clear policies should be implemented to eliminate unwarranted isolation or segregation of transsexual and transgendered prisoners.

Aftercare

Many prisoners with HIV/AIDS first seek medical and community supports for their illness during incarceration. Therefore, transsexual and transgendered prisoners with HIV/AIDS who receive health care during their incarceration should be supported in continuing to access appropriate care after their release. Correctional services, both federal and provincial, need to provide the links necessary to facilitate a continuation of care and support. These links should not be limited solely to gender identity clinics, or professionals approved by such clinics, but should also include community-based agencies that have credibility and experience working with street-involved transsexual and transgendered people, with sex-trade workers, and with ex-prisoners. Currently, many gender-positive services, supports, and treatments for the transsexual and transgendered prison population are available only outside of correctional services facilities. Mechanisms need to be put in place to ensure that these programs are available to transsexual and transgendered prisoners upon their release from prison.

To address these issues, we recommend:

1. Exit kits containing HIV/AIDS information, contacts with gender-positive community-based organizations, condoms and bleach must be made available to prisoners when they are released from custody facilities.
2. The federal and provincial correctional services should work with community-based gender-positive HIV/AIDS housing programs and service organizations to ensure that they meet the needs of transsexual and transgendered ex-prisoners. Community-based housing programs and service organizations should be supported in adapting their services to the needs of recently released transsexual and transgendered ex-prisoners with HIV/AIDS. Discharge planners, correctional social workers, and case management officers must be educated on the availability of, and programs offered by, HIV/AIDS supportive housing in their regions. The National Parole Board must be similarly educated on the benefits offered by community-based HIV/AIDS supportive housing so that they can fairly and accurately assess the parole plans of transsexual and transgendered prisoners with HIV/AIDS.

– *Ann V Scott & Rick Lines*

Ann Scott has been working with the male-to-female transsexual and transgendered community since 1989 and has been involved with PASAN since 1997. Rick Lines has been employed as the Prison Outreach Coordinator for PASAN since 1993. Ann can be reached at <cscott@cw-eng.com>. Rick can be reached at <ganainm@ican.net>.

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[1] PASAN. *HIV/AIDS in the Male-to-Female Transsexual and Transgendered Prison Population: A Comprehensive Strategy*. Toronto: PASAN, 1998. Copies of the document are available from PASAN at 489 College Street, Suite 405, Toronto, Ontario M6G 1A5 or telephone (416) 920-9567.

[2] K Namaste. Access Denied: A Report on the Experiences of Transsexuals and Transgenderists with Health Care and Social Services in Ontario. Toronto: Project Affirmation, 1995. Although "transgender" is considered the umbrella term, the term "transsexual and transgendered" is used throughout this article in an effort to be as inclusive as possible. Some transsexuals do not consider themselves transgendered, and vice-versa.

[3] Ibid.

[4] Ibid.

[5] As cited by W Travers, at the Transgendered Youth Workshop in Toronto in 1996.

[6] K Namaste. Évaluation des besoins: Les travesti(e)s et transsexuel(le)s à l'égard du VIH/sida. May 1998. Unpublished.

[7] R Jürgens. Update on Needle and Syringe Exchange in Swiss Prisons. *Canadian HIV/AIDS Policy & Law Newsletter* 1996: 1(4): 2-3; J Jacob. Germany – Needle Exchange in Prisons in Lower Saxony: Preliminary Review. *Canadian HIV/AIDS Policy & Law Newsletter* 1997: 3(2/3): 30. Preliminary Review. *Canadian HIV/AIDS Policy & Law Newsletter* 1997: 3(2/3): 30.

Needle Distribution in the Swiss Prison Setting: A Breakthrough?

The Swiss experience with needle distribution in prisons, presented at the 12th World AIDS Conference by Dina Zeegers Paget, is significant because it shows that harm-reduction measures can be successfully implemented in prison settings.

Issue

Switzerland was the first country to set up a scientifically evaluated pilot project on needle distribution in a prison setting. To date, a small number of prisons have followed this example. However, most prisons have been hesitant to do so, since there was no official political statement on the legality of such projects. This changed in October 1997, when the Swiss Federal Office of Justice (SFOJ) issued a statement on the legality and even necessity of implementing effective HIV prevention measures in the prison setting. It is expected that this statement will help overcome the hesitance of prisons and prison authorities.

Background Information

Switzerland is a country of seven million inhabitants. It is a federal state with 26 semi-autonomous cantons. Prosecution, sentencing, and institutional measures fall under the jurisdiction of the cantons. There are about 150 prisons in Switzerland, and in 1996 the average number of prisoners was 4197 in prisons and 1693 in remand centres. HIV and hepatitis are real problems in our prisons. HIV prevalence is between 1.8 and 2.9 percent among men and around 3.0 percent among women (Karger, 1998). Hepatitis prevalence is estimated to be as follows (Karger, 1998):

Estimated prevalence:	Men	Women
Hepatitis A	0.1-0.3%.	5.9-17.1%
Hepatitis B	0.8-2.4%	4.6-5.6%
Hepatitis C	2.1-2.7%	4.6-7.7%

Because these diseases are transmitted mainly through the sharing of injection equipment, exchanging old needles for new sterile ones seems an effective means of preventing transmission. However, giving out needles in the prison setting is controversial.

Historical Overview

As far back as 1988, the prison doctor at the Hindelbank prison for women started distributing sterile needles to drug-using prisoners. On finding out about this, the prison inspector prohibited the further distribution of needles.

In 1991, a survey of the medical service in Hindelbank proved that needle sharing occurs and that there was thus a real risk of HIV infection.

In 1992, the prison doctor of the Oberschöngrün prison for men started distributing sterile needles to drug-using prisoners. This was accepted by the prison governor and has continued ever since.

> As far back as 1988, the prison doctor at the Hindelbank prison for women started distributing sterile needles to drug-using prisoners.

In the same year, the SFOJ published an expert report on the legal admissibility of needle distribution and disinfection programs in the prison setting as pilot projects.

In 1993, the Swiss Federal Office of Public Health (SFOPH) published its new strategy, which included the following objectives:

- By the end of 1995, the following pilot projects should have been initiated in remand centres and prisons: distribution of sterile injection equipment; and diversified (controlled) issuing and prescription of drugs.
- By the end of 1997, those HIV-prevention pilot projects involving the distribution of syringes should be evaluated, and the appropriate conclusions drawn.

In 1994, the official pilot project at the Hindelbank prison for women was started. In this project, sterile needles and syringes could be obtained through automated syringe-exchange dispensers. The external evaluation showed the following results:

- drug consumption did not increase with the availability of sterile needles;
- needles and syringes were not used as weapons;
- the health status of drug users improved;
- the sharing of needles decreased enormously; and
- no new cases of HIV and hepatitis infection were found.

A second evaluation in 1996 confirmed these positive results. The pilot project has been integrated into the normal activities of the prison.

In 1996, the health department of the Canton of Geneva adopted a decision to allow the prison doctor of Champ-Dollon to distribute needles to drug-using prisoners.

The Canton of Graubünden decided to implement a pilot project on needle distribution in the Realta prison for men; it started in February 1997. Sterile needles can be obtained through one automated dispenser in a one-for-one exchange. Preliminary results are positive. External results will be published in March 1999.

In 1997, the doctor in the central prison of Luzern started distributing needles to drug-using prisoners.

New Developments

A clear stand on the legality of needle distribution in the prison setting was issued by the SFOJ in October 1997. It concluded that prison authorities have a duty to adopt effective measures to prevention HIV transmission. There is a duty to distribute needles, but it is not obligatory as long as other effective measures have been adopted.

The Canton of Berne adopted a decision on 1 December 1997 to the effect that all four major prisons (Hindelbank, Witzwil, St Johannsen, and Thorberg) would distribute needles to drug-using prisoners by 1 July 1998 at the latest. All but one (St Johannsen) had put these measures into place by that date.

In March 1998, the SFOPH sent these two decisions to all cantonal health and justice authorities, recommending that they integrate needle and condom distribution programs in all prisons. Following this, a large number of cantons have discussed the issue at the political or administrative level.

> In October 1997, the Swiss Federal Office of Justice issued a statement on the legality and even necessity of implementing effective HIV prevention measures in the prison setting.

In Zürich, the justice department asked all prisons to state whether needle distribution is necessary or not. It was expressed that needle distribution was not (yet) an option. A decision is still pending. In Jura, a cantonal commission was asked by the health minister to issue a statement. That statement is still awaited. In Appenzell Ausser-Rhoden, the issue was discussed at the cantonal political level. An internal working group was set up to draft a proposal. In St Gallen, a working group with justice and health representatives agreed that needle distribution in the prison setting is necessary. Implementation of the decision awaits the Realta results. In Aargau, the issue was discussed between prison and justice authorities, after which it was decided that, for the time being, needle distribution was not necessary. In Vaud, the issue has been taken up by the cantonal prison medical service. In Ticino, the cantonal physician has asked the prison to verify whether there is drug use in the prison, following which further steps will be discussed. And in Basel-Stadt, the issue of needle distribution in the prison setting has been discussed for a long time. It is hoped that the SFOJ statement will encourage further discussions.

Conclusions

Switzerland has taken a pragmatic approach to harm-reduction measures, in particular needle distribution, in the prison setting. This has led to some successes, well documented by the experiences in both Hindelbank and Realta. This pragmatic approach has helped promote discussion of the issue at the legal and political level and has facilitated the clarification of legal questions in this field.

The 1997 official federal statement on the legality of needle distribution in the prison setting has encouraged discussion of the issue in at least seven cantons.

In the Canton of Berne, the 1997 statement has led to a breakthrough, with all major prisons implementing needle distribution since 1 July 1998.

– presented by Dina Zeegers Paget

Until January 1999, Dina Zeegers Paget, LLM, PhD, worked at the AIDS Unit of the Swiss Federal Office of Public Health in Berne. She now manages the European Public Health Association. The Swiss Federal Office of Public Health can be contacted for more information: Mark Ita, AIDS Unit, email: <mark.ita@bag.admin.ch>.

For further reading:

1. J Nelles, A Fuhrer. Drug and HIV prevention at the Hindelbank penitentiary. Abridged report of the evaluation results of the pilot project. Berne: SFOPH, 1995.

2. R Jürgens. *HIV/AIDS in Prisons: Final Report.* Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1996.

3. J Nelles, A Fuhrer (eds). *Harm Reduction in Prison: Strategies against Drugs, AIDS and Risk Behaviour.* Berne: Peter Lang, 1997.

4. HJ Patzen. Realta HIV- und Hepatitis-Präventions-prophylaxe, Massnahmenpaket 1995-1997. Internal evaluation report, 1997.

5. HP Hirsbrunner, V Hercek et al. Nachevaluation der Drogen- und HIV-Prävention in den Anstalten in Hindelbank. Berne: SFOPH, 1997.

6. Swiss Federal Office of Statistics. Die Gesundheit der Insassen in Schweizer Gefängnissen 1993. Berne: SFOS, 1998.

7. T Karger. Behandlung von Suchtmittelabhängigkeit und Massnahmen zur Infektionsprophylaxe im Strafvollzug der Schweiz: Eine Zusammenfassung zweier empirischer Studien. Zürich: Addiction Research Institute, 1998.

Prison and Drugs: Toward European Guidelines

Any approach to solving the problems posed by the use of drugs in prisons must include both abstinence and harm-reduction measures. This was one of the central conclusions of the Prison and Drugs 1998 Conference held on 12-14 March 1998 in Oldenburg, Germany. The Conference attracted over a hundred people, including senior officials from prison administrations, prison doctors, prison officers, managers and staff of non-governmental organizations, probation officers, and social workers. In this article, Jutta Jacob and Heino Stoever of Carl von Ossietzky University, and Alex Stevens of the University of Kent, report on the results of the Conference. The article summarizes key points made during presentations at the Conference. It lists general principles for prison drugs and HIV/AIDS services that were agreed to by Conference participants and presents three sets of recommendations that emerged from the Conference: general recommendations, recommendations on drug-free treatment, and recommendations on needle-exchange programs.

The Prison and Drugs 1998 Conference was organized by the European Network of Drug and HIV/AIDS Services in Prison (ENDHASP), which is coordinated by Cranstoun Drug Services of London, England, and the Carl von Ossietzky University in Oldenburg. The central aim of the Conference was to exchange information, to harness the expertise of people working in the prisons, and to develop recommendations on five topics related to prisons: harm reduction, drug-free treatment, substitution treatment, needle exchange, and peer support.

Conference Summary

The opening address at the Conference was made by Heidrun Alm-Merk, Minister of Justice of Lower Saxony, one of the German *Länder* (states), who was instrumental in persuading two prisons to start the first needle-exchange schemes in German prisons (at Vechta and Lingen institutions). Ms Alm-Merk emphasized the importance of the principle of equivalence of drug and HIV/AIDS services inside and outside prisons: inmates who use drugs should have access to the same prevention services for HIV/AIDS and hepatitis as people on the outside.

During the Conference it became clear that there is a wide range of policies in Europe concerning drugs and HIV/AIDS services in prison. Some countries emphasize drug-free policies, such as the United Kingdom, with its policy of mandatory drug testing, and the Netherlands, where drug-free units have been developed over the last 20 years. Other countries integrate harm-reduction measures, such as Germany and Switzerland, where methadone treatment and needle-exchange programs have been introduced.

There was a consensus that no single approach will solve the current problems. Measures for harm reduction are needed as well as measures promoting abstinence. It is necessary to integrate both approaches and to maintain a balance. As Arie van den Hurk pointed out in his speech on "Drug-Free Units":

> Present services are too much focussed on abstinence. This is not very realistic considering developments within the target group. This means that expansion is needed from "cure" to "care." In other words, there is an increasing need for intervention.

Franz Trautmann, in his speech on "Peer Support and Risk Reduction Activities in Prison," emphasized that in the face of the increasing numbers of inmates who use drugs in European prisons, and the dangers of drug-related harm and communicable diseases, implementation of risk-reduction strategies in prisons is urgently needed. These strategies would broaden the range of measures that are currently used in drug-free treatment and methadone detoxification programs. However, Trautmann said, it is also clear that the risk-reduction approach is relatively new to the prison system and is often perceived as a threat to traditional abstinence-oriented drug policies.

Dr Heino Stoever presented an overview of the characteristics of prison needle exchanges in Europe. As of 1998 there were ten prisons in Europe running needle-exchange programs using different models for providing sterile syringes. At least three more institutions (all in Germany) were planning to introduce such programs [additional prisons in Switzerland have since introduced such programs; see the article by Zeegers Paget in this issue of the *Newsletter*]. What we know so far from the scientific evaluations in Germany and Switzerland is that:

- The needle-exchange programs are feasible (ie, they can be integrated into the organizational framework of a prison).

- The programs are accepted by the various stakeholders (inmates, staff, and prison management).
- The programs do not lead to an increase in drug use.
- The programs have not resulted in any threatening scenarios.
- The programs are successful in helping inmates avoid needle sharing.
- No new infections of HIV or hepatitis among participants in the needle-exchange programs have been documented.
- The programs help to improve the health status of inmates who use drugs.
- The programs expose the contradictions between control and care and promote reflection on these conflicting roles.
- The programs must be accompanied by prevention and information measures.

General Principles

Participants at the Oldenburg Conference agreed on the following general principles for prison drug and HIV/AIDS services:

- A wide range of drug services should be available to prisoners, based on local and individual need.
- Health services for prisoners should be equivalent to those provided outside prisons.
- There should be continuity of treatment for prisoners entering and leaving prison, involving cooperation between prisons and external agencies.
- There should be training for prison staff and prisoners on drugs and related health problems.
- Drug services in prisons should be subject to monitoring and evaluation.

Participants at the Conference also developed a series of recommendations for prison drug and HIV/AIDS services. The recommendations fall into three categories: general recommendations; recommendations on drug-free treatment; and recommendations on needle-exchange programs. They are presented below.

General Recommendations

- Prison should be seen as one part of a continuum (from society to the criminal justice system and back again). This continuum should provide a process of proactive interventions, including assessment, admission, treatment, relapse prevention, and aftercare.
- Policy and strategy to tackle drug use in prison should be backed up by legislation and should ensure that national minimum standards for treatment and security are implemented in all institutions. Additionally, there must be room for individual initiatives, pilot projects, and innovative programs.
- Programs should be provided according to individual needs. Offending behaviour might not be drug-related. If such behaviour is related to drugs, both the primary cause and the drug abuse must be treated.
- The subject of addiction must be included in the continuing education and training of prison staff, including medical staff.
- There must be regular opportunities for exchange of information and best practices between prisons and outside agencies at all levels.
- The health of prisoners is paramount. Therefore, treatment options and access to them must be sufficient and must be based on the same quality standards as in the community.
- Treatment options must be geared toward the needs of individual prisoners.
- Legislation should be introduced to enable flexible release of prisoners, thereby actively encouraging successful participation in treatment programs for offenders.
- Prisoners should participate in treatment on the basis of voluntary and informed consent.
- Treatment in prison is not an alternative to community treatment. They are complementary. Both are necessary.
- Directors of prisons should undertake full and constructive dialogue with staff to ensure that any national initiative is implemented locally with full support and ownership by the prison.

Recommendations on Drug-Free Treatment

- Prisons should provide drug-free units: (1) for the treatment of drug users who want treatment; and (2) for other prisoners who wish to be free from pressure to use drugs. Both types of unit are important and necessary. Prospects for the long-term success of drug-free treatment can be improved if the prisoners who finish treatment are able to go to a drug-free unit.
- Drug-free treatment programs should be holistic in nature. A combination of complementary programs and treatment options should be provided. Different approaches for different subgroups are required. Drug users who decline treatment need a harm-reduction strategy.
- Close cooperation between the professionals in prisons and external organizations is very important. Programs can be successful if they involve groups in the local community who support the prison program, and who participate in relapse prevention and continuity of treatment on release. Appropriate treatment and administrative

protocols should be developed.

- Prisoners must be appropriately placed within the prison population according to the risk they pose, and programs should be delivered at the lowest level of security possible. However, serious offenders should not be denied access to a drug-free unit.
- Staff education is an important prerequisite for implementation of treatment programs. Staff attitudes, values, and responsibilities must be developed so that they can facilitate the treatment process. Successful implementation of drug-free treatment requires a vision that is shared by staff and inmates.
- All treatment programs should be monitored and evaluated on a regular basis. This would help to ensure compliance with national guidelines (where such guidelines exist).
- Public relations should be undertaken proactively, at both the national and local level, to ensure that support is available for drug-free units.
- Management should promote an overall view that sees the misuse of drugs in the context of the whole prison system. A multidisciplinary approach is important. Multidisciplinary teams, with internal and outside participation, should be involved. This will help understanding of the issues by all staff and prisoners.
- Implementation of drug-free treatment requires a vision of establishing drug-free wings, a vision that is shared by staff and inmates alike.

Recommendations on Needle-Exchange Programs

- Prisons have the responsibility to provide prisoners with access to adequate measures to prevent infection and promote health.
- Because needle exchange is a sensitive area for prison services in many European countries, independent surveys should be carried out in prisons that are considering the introduction of needle exchange to determine the extent of injection drug use within the prison prior to implementation.
- Needle-exchange programs can be a useful and integral part of a general approach to drug and health services in prisons. They should constitute one of a range of services that includes health-promotion measures, counselling, drug-free treatment, and substitution treatment.
- To protect all parties participating in infection prevention and health-promotion measures (such as needle exchange), legal ramifications must be clarified before the measures are introduced. It is particularly important to clarify legal issues for special groups, such as juveniles and inmates in substitution treatment. Clarification of these issues is the responsibility of the government department involved. The results should be published.
- The choice of distribution method, either through machines or through personal contact, depends on specific conditions within the respective prison settings. Continuity of availability of sterile syringes should be guaranteed, whether distributed by prison or community staff.
- The successful implementation of needle-exchange programs in prison requires establishing and maintaining acceptance among the prison staff and inmates, political and legal authorities, professionals, and the public at large.
- Participation in needle-exchange programs should be strictly confidential, so that the participants need not fear negative consequences during their remaining sentence.
- The distribution facilities should be located in easily accessible areas.
- Effective infection prevention can only be achieved if provision of prevention measures is supplemented by counselling and information. Mandatory education and voluntary training for inmates and prison staff at all participating levels should be implemented and should particularly address the following issues: basic knowledge about drug consumption and infection risks; means of transmission and infection prevention; safer use and safer sex; and drug-related first aid.

Next Steps

Another conference was held in Marseilles, France in May 1998 on the topic of "Prison and Drugs: Youth and Women." An integrated set of recommendations of these two conference will serve as a basis for future prison drug and HIV/AIDS services and will be distributed before the 4th European Conference on Drug and HIV/AIDS Services, to be held in Vienna, Austria in December 1999.

– Jutta Jacob, Alex Stevens, and Heino Stoever

Jutta Jacob is a psychologist at Carl von Ossietzky University, Oldenburg, Germany. Alex Stevens is teacher at the University of Kent, England. Dr Heino Stoever is a social scientist at Carl von Ossietzky University. Jutta and Heino can be reached at <infekt@psychologie.uni-oldenburg.de>.

Further information on the pilot needle-exchange project in Vechta and Lingen institutions can be obtained at <www.uni-oldenburg.de/fb3/politik2/infekt/infekt.html>.

An article providing further information on "Drug Use, Drug Control and Drug Services in German Prisons – Contradictions, Insufficiencies and Innovative Approaches" can be obtained at <www.drugtext.nl/articles/glasgow3.htm>.

INSURANCE

Current Issues in HIV/AIDS and Insurance: Part II

This is the second in a two-part series on HIV/AIDS and insurance. In Part I (published in the last issue of the *Newsletter*), we used a fictional scenario to explore some questions about obtaining insurance coverage. In this second part, again using a fictional scenario, we explore some questions about accessing benefits once one has become insured.

Scenario

George is a partner in the small law firm of Dewey, Cheatem & Howe. He has been low-key about his HIV-positive status but has confided in a few of his partners. George lives with his spouse Clara, and he depends on his insurance benefits at work to cover his drug costs. George receives a memo telling him that the firm has changed the company with which it holds insurance for employees, entailing a new policy with new terms concerning the scope of benefits covered. George discovers that the new insurance carrier's policy includes a clause stating that the costs of drugs for HIV-related conditions are only covered to a maximum of $500 a year, which is a small fraction of his costs. (Sadly, as is too often the case, George is learning this when it is too late to do anything to prevent the change. As a partner of the law firm, he might have anticipated greater entitlement than an employee in similar circumstances.) Clara notices that George has not been himself lately and has been uncharacteristically withdrawn and poorly groomed. George complains that he is being hassled about his performance at work. Suddenly, George tells Clara that he has quit the firm "to escape the stress." He has accepted a position with the ABC Corporation's legal department. The salary is lower than in his previous position and Clara expresses concern about insurance. George tells her that the new job includes good benefits. A few months later, his behaviour having become increasingly erratic, George is fired from his new job. Clara is distraught, and is even more concerned when she learns that George has now been diagnosed as suffering from AIDS-related neurological problems. Clara seeks drug benefits and long-term disability benefits from both employers' disability insurance carriers. Both flatly refuse to pay. Clara consults a lawyer, who tells her a lawsuit would last for years.

This scenario raises a number of issues that confront HIV-positive people seeking to access insurance benefits under their policies.

In the case of a large pool of employees, the high drug costs of a few employees are more than offset by the lack of claims from the rest of the employees.

Change in Insurance Coverage

The first problem is the first employer's change in insurance carrier and the consequent change in coverage. Small businesses often have difficulty maintaining coverage for drug expenses. The more claims the insurance company has to pay out under a policy, the less profit it makes on the premiums it charges for providing that coverage. In order to make the same profit on selling the insurance coverage, the insurance company therefore passes these costs back to the members of the insurance plan by charging higher premiums to provide the same benefits coverage, spreading the insurance company's cost of making these payments over the whole pool of employees. In the case of a large pool of employees, the high drug costs of a few employees are more than offset by the lack of claims from the rest of the employees; in the case of a small pool, the high drug costs of a few employees are not offset to the same degree, meaning less profit for the insurance carrier unless it raises the premiums it charges. Facing increased premiums, the employer seeks to reduce the cost of maintaining some insurance for employees by purchasing less generous benefits coverage. In George's case, the new policy caps the amount the insurance company is liable to pay to cover an employee's drug expenses.

While the issue is raised frequently in the United States, the attempt to put limits on insurance coverage for HIV/AIDS-related medical expenses has only been considered in Canada in the context of "group creditor" insurance (ie, insurance that people purchase to ensure that, if something untoward happens, they will have money to make their mortgage payments on their house).[1] However, as discussed in Part I of this series, in the case of *Gibbs* v *North Battleford Co-Op*,[2] the Supreme Court considered a complaint about a group disability insurance policy that contained more onerous eligibility requirements for coverage in the case of mental disabilities than for physical disabilities. The Court ruled that, once disability was insured, the employer violated human rights law by discriminating between types of disabilities. Using the same logic, it is likely that the employer's policy, which discriminates against George by imposing a cap on HIV/AIDS-related drug costs (but not on drug costs related to other conditions), is illegal, and that George's additional costs are recoverable.

"Pre-Existing Condition" Clauses and "Job Lock"

This case also illustrates the problem of "job lock." As discussed in Part I, HIV status is still relevant in the context of many insurance applications. Once an HIV-positive person has qualified for insurance benefits under a given policy, they put those benefits in danger by leaving their current work for a new position because they will probably not be able to re-qualify under the terms of the new policy, as they are deemed "uninsurable" because of their HIV status. As a result, people are sometimes "locked" into jobs they do not like simply to protect their benefits. This situation has been remedied in the US[3] and in Québec by legislation that requires "portability" of employee insurance benefits programs, meaning the employee can maintain their existing insurance coverage despite the change in job.

George's new employer probably has a "pre-existing condition" clause in its insurance policy. Such a clause limits the extent of the insurance carrier's liability for covering claims made by new employees who claim long-term disability (LTD) benefits for illnesses or conditions that were "pre-existing" when they qualified for coverage under the policy. Typically, such a clause excludes any claim made by an employee within one year of starting their employment, for any condition concerning which treatment had been received within 90 days before beginning employment. Such clauses were upheld as legally sound in *Thornton* v *North American Life*.[4] In that case, the court reasoned that, because the insurer providing group insurance was spreading the risk over the entire group of employees (rather than assessing the risk of claims presented by each individual employee), and since employees thus provided less detailed medical information when they joined the insured group, "pre-existing condition" clauses were the only way for the insurance company to protect itself against the "undue risk" of having to cover employees who join the group with pre-existing health conditions that may result in disability claims.

Relationship between Disability, Employment Performance, and Accessing Disability Benefits

The case also raises the problem of employment performance issues, which are typically bound up with insurance issues. Often, the person is reluctant to claim disability and the accompanying benefits coverage for fear of "outing" themselves as HIV-positive or as gay. They risk losing their job if their performance is hindered because of disability, yet if they file a disability claim the insurer may take the view that they are not disabled from working and that their job difficulty was due to ordinary performance problems not related to any disability. Whether, and when, to "jump" is a delicate problem, best made in consultation with physicians and experienced lawyers in advance.

In addition, the lawyer may wish to consider whether there might also be possible legal claims of discrimination (in breach of human rights statutes), wrongful dismissal claims for termination without cause and without adequate notice (or pay in lieu of a notice period), or breach of a fiduciary duty owed by the insurance company to the insured. It is not uncommon to have such cases launched with a claim for LTD benefits under the insurance policy as an alternative or supplementary claim. In a wrongful dismissal action, a court will compensate for loss of insurance benefits. Given that George is now "uninsurable" because of his health condition, it may be difficult to quantify (ie, put a figure on) the value of his lost benefits, and this is also an issue that has yet to be considered by our courts. Depending on the facts in any particular case, there may also be grounds for a human rights complaint of discrimination (eg, based on disability or sexual orientation). Under human rights law, an employer is required to make "reasonable accommodation" for an employee with a disability, short of incurring "undue hardship," so as to enable that employee to keep their job if they can perform its essential duties. While a human rights tribunal could, if it found discrimination, order the employer to reinstate the employee, it is not clear that it could compel an insurer to re-admit an HIV-positive person to a group insurance plan.

This scenario also highlights the pernicious nature of HIV-related neurological problems. A significant percentage of people with HIV infection experience depression, impaired judgment, and eventual neurological problems. For many conditions, such as HIV dementia and progressive multifocal leukoencephalopathy, the symptoms present in a slowly emerging pattern of behaviour and personality changes. These odd outward manifestations are the tip of the iceberg of significant cognitive problems and impaired judgment.

In the recent case of *Spring* v *Standard Life*,[5] where the plaintiff sued an insurance company to obtain his disability benefits under the policy, Mr Justice Gans of the Ontario Court (General Division) noted these scientific facts and wrestled with retrospectively determining when the plaintiff's condition first manifested itself. He determined that the illness was present before the end of the employment and that it had "disabled" the employee within the meaning of the insurance policy. Furthermore, the condition itself prevented the employee from appreciating his disabled condition, which was similar to a case previously decided by the same court.[6] Following that earlier decision, Justice Gans ruled that it was irrelevant that the employee had been terminated before he filed his LTD claim. In other words, if the person became disabled while covered by the insurance policy as an employee, their subsequent termination from their job is irrelevant. However, it will always be a question of evidence whether the employee's work-related problems were caused by a disabling condition (such as AIDS) or were not related to the disability. Additionally, most policies contain a time limit for filing a claim, so Clara and George will have to consider the issue immediately.[7]

Return-to-Work Issues

Even if George was disabled, now that he has been diagnosed his health may improve, given current treatments. George will have to contemplate a return to the workforce, an issue facing many people with HIV/AIDS at present. This involves a number of complex issues, including his ability to work and the impact of working on his health. For many people with HIV/AIDS, the burning issue is the loss of income security afforded by LTD payments and the fact that they may have difficulty regaining those benefits with a new employer because of a "pre-existing condition" clause, as discussed above.

If George is lucky, his LTD insurer will have a progressive attitude toward rehabilitation and will work with him on a graduated return-to-work plan. Unfortunately, however, many insurers do insist on their right to proof of "ongoing total disability" before continuing to pay LTD benefits. As a result of the Supreme Court ruling in *Paul Revere Life Insurance Co* v *Sucharov*,[8] "total disability" does not mean 100 percent physical incapacity. Rather, it means inability to perform the "essential duties" of one's pre-disability job or, after a certain period of time (eg, 24 months), the essential duties of "any job for which the person is reasonably fitted by education, training or experience." (This is the language most typically found in group LTD policies.) However, the insurance company may refuse to accept that George is "totally disabled," and disability that is only partial may preclude him from continuing to receive benefits while simultaneously impairing his employment prospects.

Litigating: Costs and Possible Interim Solutions

The problem that Clara faces is a very practical one. She and George have lived from paycheque to paycheque; they now face a battle with two employers and their insurers, with no income, while shouldering the costs of George's drugs and litigation. Defendants are not above "playing hardball" to drag out a case and run up the legal costs for the plaintiff, whom they know can ill afford them. However, there are several things that may help with the problem.

Insurance companies are powerful, long-lived opponents with considerable resources.

Clearly, any government relief programs should be accessed immediately. Frequently, the lawyer is better advised to refer the client to a community-based agency with expertise in this field rather than attempt to access these programs for the client. It also pays to marshal the evidence for the lawsuit quickly and to seek an early settlement, as the insurance company and the employer concerned may not have been aware of the full medical situation and may not appreciate their potential exposure to legal liability.

However, if a quick settlement cannot be reached, there may be a possibility of interim relief until the lawsuit is resolved. In the case of *Watkin* v *Bennet Best Burn*,[9] the plaintiff moved for an injunction; on the consent of both sides, the Court ordered that group benefits be maintained while the litigation proceeded. This order was later varied, but some ongoing protection for the plaintiff was provided pending trial. More important, it is clear from the order made by Mr Justice Sharpe, a noted authority on the law of injunctions, that such orders can be made in appropriate circumstances. Old legal tools such as injunctions can be pressed into service in meeting the new challenges of HIV/AIDS.

Other cases also indicate that interim relief may be available. In the *Spring* case mentioned earlier, the insurance company Standard Life has appealed the trial court's judgment ordering it to pay LTD benefits. As a general rule, this would "stay" the judgment pending the outcome of the appeal. However, the Ontario Court of Appeal lifted that stay, requiring Standard Life to make monthly LTD benefit payments pending the hearing of the appeal. Similarly, in *Thwaites* v *Canada (Attorney General*),[10] the Federal Court of Canada (Trial Division) ordered the full payment of a human rights commission award pending an appeal, given the progressive nature of HIV disease.

In *Spring,* the trial judge's decision on the issue of legal costs is also helpful. Following precedents in this area, Justice Gans ordered that the insurance company pay almost the complete legal costs of the plaintiff, a man with AIDS suing for group LTD benefits, because it had played "hard ball."[11]

Need for Reform

These legal developments may make it easier to afford litigation to enforce entitlements to insurance benefits. In addition, alternative dispute resolution (ADR) mechanisms may facilitate early resolution of disputes, or court "case management" rules may speed up the litigation process. But these are not adequate. HIV causes poverty. Not everyone who is, or will become, infected has the privilege of obtaining insurance, but those who do often do not know their rights, risk losing their insurance, and face costly and lengthy battles to obtain benefits to which they are entitled, in the course of which they may die. Insurance companies are powerful, long-lived opponents with considerable resources.

There remains a real need for reform in this area. The entire group insurance benefit field is largely unregulated, or is awkwardly regulated. Insurance policies themselves are often inaccessible to members of group plans, and incomprehensible to those who do have access to them. Unfortunately, most insurance statutes are ponderous and out of date. Governments appear reluctant to embark on amending legislation, which is not a burning issue for most voters. In the interim, lawyers and other advocates helping people with HIV/AIDS in this field will have to work with and improve existing tools. One important tool on the informational front is *HIV/AIDS: A Guide to Insurance Benefits*,[12] an invaluable resource for lawyers and AIDS service organizations.

Some suggestions for legislative change would include the following:

- As has been done in Québec and the US, requiring portability of group insurance benefits, meaning that "pre-existing condition" clauses would not apply to persons changing from one plan to another as a result of changing employment.
- Members of group plans should have a direct right of access to their group policy.
- Employers should be required to maintain group benefits coverage for employees on long-term disability leave.
- Strict time limits should be imposed on insurers for assess-

Continued from previous page.

ing claims for LTD benefits; claimants who establish a prima facie entitlement, by motion before a court, should be entitled to receive their benefits pending trial, notwithstanding the insurer's denial that they qualify as "totally disabled" under the policy.
- Persons formerly on LTD should be allowed a one-year grace period to attempt re-entry into the workforce, and if they are unable to do so due to illness, to return to receiving LTD benefits without penalty.

– Douglas Elliott

Douglas Elliott is a partner at Elliott, Kim, Toronto. He can be reached at <rde@elliottandkim.on.ca>.

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[1] See Part I of this article: *Canadian HIV/AIDS Policy & Law Newsletter* 1997/98; 3(4)/4(1): 1, 50-53, with reference to British Columbia Ministry of Finance. *Information Bulletin*. Bulletin number INS-95002 (16 January 1995) regarding ruling of BC Superintendent of Insurance.

[2] (1994), 24 CCLI (2d) 1.

[3] *Health Insurance Portability and Accountability Act* (HIPAA), HR 3103, 104th Cong (1996).

[4] (1995), 28 CCLI (2d) 4 at 9-11 (Ont Ct Gen Div).

[5] (1998), 1 CCLI (3d) 167 (Ont Ct Gen Div). This case is under appeal.

[6] *Tarailo* v *Allied Chemical Canada Ltd* (1989), 68 OR (2d) 288 (HC).

[7] In certain circumstances, courts do appear to have the power to permit a claim to proceed even if not filed in a timely fashion. See *The Maritime Life Assurance Co* v *Saskatchewan River Bungalows Ltd*, [1994]2 SCR 490.

[8] [1982] 2 SCR 54.

[9] (31 July 1995), Toronto 95-CU-86709 (Ont Ct Gen Div).

[10] (1993), 19 CHRR D/308 (FCTD).

[11] (1998), 1 CCLI (3d) 187 (Ont Ct Gen Div).

[12] Canadian AIDS Society & AIDS Committee of Toronto, 1998.

EMPLOYMENT

The Canadian AIDS Society's Labour Force Participation Project for People with HIV/AIDS

Due to recent clinical advances in the treatment of HIV disease, many people with HIV/AIDS are now living longer and healthier lives. While they continue to face uncertainty about their long-term health prospects, some are nevertheless considering returning to the labour force on a part-time or full-time basis. As well, those currently employed may require mechanisms to ensure they are able to continue working without compromising their health. While there are incentives to participate in the labour force, the possibility of returning to work raises a number of complex questions that have not been comprehensively addressed to date. This article, which follows on a series of articles on return-to-work issues published in the last issue of the *Newsletter*,[1] summarizes the recently released results of a national research project on labour force participation issues undertaken by the Canadian AIDS Society.

Introduction

To address the need for more comprehensive information on return-to-work and other labour force participation issues for people with HIV/AIDS, the Canadian AIDS Society (CAS) coordinated an eight-month national research project from December 1997 to July 1998. The project had two major goals:

- to establish a comprehensive understanding of labour force attachment issues for people living with HIV/AIDS; and
- to increase awareness among consumers, community organizations, and public and private sector service providers of the workforce integration needs of people with HIV/AIDS.

The project built on work already completed or currently in progress by a number of community-based organizations;[2] it was guided by a national advisory committee of community representatives with expertise in return-to-work and benefits-counseling issues.

Research Activities

Research activities included an environmental scan, regional consultations, a national survey, and a review of federal and provincial income assistance programs for people with disabilities.

Environmental Scan

An environmental scan was conducted to identify the broader environmental factors affecting labour force participation for people with HIV/AIDS. This process highlighted the importance of developing an ethical framework to address return-to-work decisions, particularly in the face of potential coercion by private and public disability support programs seeking to reduce costs and caseloads.

The Canadian disability system, private and public, has become a minefield for people with HIV/AIDS.

The respective roles of provincial and federal governments with regard to disability issues are evolving rapidly, with disability programs experiencing the cost-cutting measures affecting other sectors of the Canadian health-care system. The Canadian disability system, private and public, has become a minefield for people with HIV/AIDS.

Discrimination and stigmatization continue to affect the workplace, and the situation is complicated by the necessity of managing complex treatment regimens and their side effects.

The changing structure of the labour market affects the readiness of people with HIV/AIDS to return to work. Structural issues include fewer full-time and more part-time or contract positions, technological change, competitive pressure on employers to reduce benefits, and an increase in poorly paid service-sector jobs with fewer benefits.

The fluctuating nature of HIV disease and the lack of knowledge of HIV issues among traditional disability service providers also challenge any attempt to ensure access to relevant programs for people with HIV/AIDS. Discrimination and stigmatization continue to affect the workplace, and the situation is complicated by the necessity of managing complex treatment regimens and their side effects.

Finally, there are psychosocial factors that affect individual readiness to enter the workforce: the ongoing uncertainty around long-term health, others' expectations, fear of financial instability and more general concern over the many unknowns involved in making critical decisions about the future.

Regional Consultations

Seven consultations were held in Halifax, Montréal, Toronto, Winnipeg, Edmonton, and Vancouver, with over 100 people with HIV/AIDS. Each consultation included a session in which people could raise issues with specific stakeholder groups, including public and private benefit program administrators, vocational rehabilitation service providers, AIDS service organizations, and disability organizations.

Participants in these consultations raised key concerns with respect to (re)entering the workforce:

- the possibility of having disability benefits revoked;
- losing drug and other health coverage;
- discrimination and accommodation in the workplace; and
- the need for appropriate vocational rehabilitation, training, and education.

Consultation participants also expressed a desire for community AIDS organizations to take the lead in workplace education and support for people with HIV/AIDS in negotiating decision-making about a possible return to work.

The dialogue between people with HIV/AIDS and various stakeholder groups at the consultations provided an important forum for information exchange and ensured the project included the perspectives of a variety of stakeholders. Many stakeholder groups expressed a desire for more information on the labour-market barriers facing people with HIV/AIDS and a willingness to work more closely with community organizations on this issue.

National Survey

Data from a national survey reinforced the concerns expressed in the consultations and provided the project with details about the views of people with HIV/AIDS on labour force issues.

Over 1400 people with HIV/AIDS from across Canada completed the survey. Thirty-seven percent of respondents were currently employed, and 20 percent of those currently unemployed were actively looking for work. The greatest concern for those who were considering returning to work was the loss of disability benefits and drug coverage. Fifty-eight percent of respondents were currently receiving disability benefits; almost half of them had been questioned about their disability status, usually by their benefit provider.

Other important concerns for those considering returning to the paid workforce were uncertainty over health status, fear of discrimination and stigma in the workplace, managing treatment schedules and side effects, and explaining an absence from the paid workforce.

Of the supports required to assist people to (re)enter the workplace, training or retraining received the highest rating in terms of helpfulness, with community-based assistance in job searching also identified as important.

The survey also confirmed that most people with HIV/AIDS are poor: almost 60 percent reported annual incomes under $20,000.

> The greatest concern for those who were considering returning to work was the loss of disability benefits and drug coverage.

Review of Federal and Provincial Programs

The program review revealed significant jurisdictional differences in the way disability support programs are administered and what criteria are used to define disability. The federal Canada Pension Plan (CPP) Disability Benefit program was one of the most stringent, but several provincial programs were also in the process of tightening eligibility criteria and implementing other changes to reduce costs and caseloads.

The review also revealed a disability system in flux, with many provincial and some federal programs undergoing substantial restructuring.Federal/provincial/territorial responsibilities with respect to disabilities are being renegotiated, and the federal government is taking a stronger leadership role in this area.

Conclusions

Overall, the research conducted by the project revealed profound concerns among people with HIV/AIDS with respect to financial security, health benefits, drug coverage, and the viability of returning to the labour force within a context of substantial uncertainty over their long-term health status. It is also clear that the lack of continuity between various disability support programs and the lack of comprehensive drug benefits are fundamental disincentives to considering a return to the paid workforce.

Recommendations

Based on the project's research findings, the National Advisory Committee made a series of recommendations on the issue of re-entering the labour market, most of which focus on the role of national, provincial, and local community organizations.

The recommendations fall into seven major categories: preserving free choice for people with HIV; benefits counseling and decision-making assistance; vocational rehabilitation and other disability support services; psychosocial issues; treatment coverage; HIV/AIDS in the workplace; and public and private disability benefit programs. They outline work required within community organizations and with other stakeholders on labour force issues, including: government at both the federal and provincial levels; public and private health and disability benefit providers; vocational rehabilitation programs; and providers of services for people with disabilities.

While some of this work is already in progress, substantial work remains at both the policy and program levels to provide a more supportive and cohesive foundation for labour force participation for people with HIV/AIDS.

People with HIV/AIDS require assistance and resources from community-based AIDS organizations and other disability groups to negotiate the complex landscape of labour force participation. National, provincial, and local AIDS organizations must work with a broad range of stakeholder groups to raise awareness about the needs of the people with HIV/AIDS in this area and to ensure that policies governing disability programs and related disability issues are sensitive to the needs of people with HIV/AIDS.

Copies of the full report on this project, entitled *Force for Change: Labour Force Participation for People Living with HIV/AIDS* (Ottawa: Canadian AIDS Society, 1998) can be obtained through the Canadian HIV/AIDS Clearinghouse at (613) 725-3434; email: <aids/sida@cpha.ca>.

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[1] See: Return to Work for Persons with HIV/AIDS: Back to the Future? *Canadian HIV/AIDS Policy & Law Newsletter* 1997/98; 3(4)/4(1): 12-13; Y Jalbert. Triple-Drug Therapy and Return to Work: Results of a Québec Study. *Canadian HIV/AIDS Policy & Law Newsletter* 1997/98; 3(4)/4(1): 13-15.

[2] See the articles in the last issue of the *Newsletter*, ibid. Another example of work that is ongoing in Canada on return-to-work issues is a document prepared by the British Columbia Persons with AIDS Society entitled Issues and Guiding Principles for Return to Work: Vocational Rehabilitation and Rehabilitation Services in the Context of HIV Infection. Vancouver: BCPWA, draft, 12 January 1998.

NEW PUBLICATIONS

Legal Responses to AIDS in Comparative Perspective[1]

Edited by Stanislaw Frankowski of the Saint Louis University School of Law, and consisting of ten chapters written by legal scholars from five continents, this book provides the most comprehensive review of legal responses to HIV/AIDS to date.

The book was designed to achieve four principal goals. First, the book was to describe, analyze, and contrast legal responses to the various aspects of HIV/AIDS in a cross-cultural perspective. Therefore, an effort was made to select highly diverse countries belonging to different families of law, countries varying in their political, ethnic, and religious backgrounds – the United States, Canada, South Africa, Australia, India, Japan, the Netherlands, Hungary, Poland, and Argentina. Second, the contributors were encouraged to explore the links between HIV/AIDS-related problems and other social issues. Third, the contributors were to reflect on the limits and effectiveness of legal measures in reducing – or at least controlling – the growth of the epidemic, and on the extent to which non-legal factors may play a role in influencing the ways societies respond to the threat of HIV/AIDS. Finally, a goal was to find how it is possible to achieve a proper balance between the need to protect society and the need to protect the rights of people with HIV/AIDS.

In his foreword to the book, Prof Lawrence Gostin calls the book "an important contribution in the fight against HIV/AIDS." He says:

> Each of the ten chapters reviews a different nation's efforts with majestic detail and clarity. ... No other book of which I am aware provides this kind of systematic coverage of the legislation and case law relating to HIV/AIDS in so many important countries. Editor Stanislaw Frankowski ... has assembled an astounding array of experts who each present authoritative accounts of AIDS law and public policy in his or her country. The authors consistently provide thorough and incisive analyses of the various countries' efforts to strike a balance between individual rights and societal interests in the midst of the HIV epidemic.

Gostin suggests that readers should use the book

> not merely to compare and contrast different legal approaches to complex public health dilemmas, but, more importantly, to examine the solutions that work (and do not work) in different countries. Careful scrutiny will reveal ... that those countries that best respect human rights and fundamental freedoms also most effectively curtail HIV infection and compassionately care for those who are ill.

He concludes by saying that,

> [a]s this book relays, it is well within the power of all governments to respect and defend the human rights of their populations. Persons living with HIV/AIDS can lead rewarding lives if free from government coercion or restraint, animus, and discrimination. An individual's right to live life with worth and dignity may transcend even the desire to be healthy. In the global fight against HIV/AIDS, fortified through law reform, human rights must be a paramount principle, not only to respect persons, but to foster public health and save lives.

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[1] S Frankowski (ed). *Legal Responses to AIDS in Comparative Perspective*. Dordrecht, the Netherlands and Cambridge, MA: Kluwer Law International, 1998 (419 pp, ISBN 90-411-1037-2, US$105).

Legal and Ethical Issues Raised by HIV/AIDS: Literature Review and Annotated Bibliography[1]

Funded by the Joint United Nations Programme on HIV/AIDS (UNAIDS), the second edition of the Canadian HIV/AIDS Legal Network's literature review and annotated bibliography was released in December 1998.

The first edition of the document had been funded by Health Canada and produced as part of the Joint Project on Legal and Ethical Issues Raised by HIV/AIDS of the Canadian HIV/AIDS Legal Network and the Canadian AIDS Society in 1995.[2] It was not meant to be a comprehensive literature review and annotated bibliography. Rather, the literature review focused on eight issues that had been identified as priority legal and ethical issues by the individuals and organizations consulted in early 1995 by the Joint Project: access to care and treatment for people with HIV/AIDS; criminal law and HIV/AIDS; discrimination; drug laws and HIV/AIDS; gay and lesbian legal issues and HIV/AIDS; legal and ethical issues raised by HIV/AIDS in prisons; laws and policies regulating prostitution and HIV/AIDS; and HIV testing and confidentiality. The annotated bibliography contained materials that met two criteria:
(1) they were of particular interest to people interested in or working on legal and ethical issues raised by HIV/AIDS; and (2) were accessible in the resource centres of Canadian community-based AIDS organizations.

The objective of the second edition was to expand the annotated bibliography by including literature originating from developing countries, and to enhance access to information on HIV/AIDS-related legal, ethical, and human rights issues by adding new sections to the document: a section featuring the Internet addresses leading to international and regional HIV-related human rights documents; and a section with information on the websites of selected organizations or institutions that contain information on legal, ethical, and human rights issues raised by HIV/AIDS. Finally, access to the document was enhanced by placing it on the Legal Network's website at <www.aidslaw.ca/biblio/tofc.htm>.

The annotated bibliography now contains more than a thousand entries in 24 different areas, from access to care and treatment, to development and HIV/AIDS, to immigration, public health, and women and HIV/AIDS.

Work on a third print edition has started. In the meantime, the Internet version of the document will be updated regularly.

A limited number of printed copies of *Legal and Ethical Issues Raised by HIV/AIDS: Literature Review and Annotated Bibliography* are available free of charge (postage and handling fees may apply, however, for requests from outside Canada) from the Canadian HIV/AIDS Clearinghouse. Tel: 613 725-3434; fax: 613 725-9826; email: <aids/sida@cpha.ca>.

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[1] R Jürgens, Bruce Waring. *Legal and Ethical Issues Raised by HIV/AIDS: Literature Review and Annotated Bibliography.* Montréal: Canadian HIV/AIDS Legal Network, 2nd edition, 1998 (ISBN 1-896735-18-5).

[2] R Jürgens. *Legal and Ethical Issues Raised by HIV/AIDS: Literature Review and Annotated Bibliography*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1995.

HIV Testing and Confidentiality: Final Report[1]

In 1997 the Joint Project on Legal and Ethical Issues Raised by HIV/AIDS of the Canadian HIV/AIDS Legal Network and the Canadian AIDS Society released a 300-page discussion paper on HIV testing and confidentiality.[2] Over a thousand printed copies of that document were distributed in Canada and internationally, and comments on it were received from a wide variety of individuals and organizations. Eighteen months after the *Discussion Paper*, a final report was recently released.

The *Report* considers the following questions:

- How has HIV testing been addressed to date in Canada?
- Should the Canadian approach to HIV testing be changed in light of new developments, including the availability of new treatments; the availability of new forms of HIV testing, in particular rapid testing and home testing, and the shifting demographics of the epidemic? In particular,
  - is *specific* informed consent to testing still necessary, or should *general* consent suffice?
  - how can access to testing be improved?
  - is pre- and post-test counseling still necessary?
  - should new forms of testing for HIV be made available in Canada?
  - do the new developments warrant any exception(s) to the principle that testing always be voluntary; is mandatory or compulsory testing or testing of specific groups of the population (or under certain circumstances) justified?
  - are there any new exceptions to the principle that testing only be done when confidentiality of results or anonymity of testing can be guaranteed?
  - should HIV and AIDS reporting provisions be changed?
  - should an approach emphasizing partner notification be adopted, and how should partner notification be undertaken?

The goal is to contribute to a process of informed and rigorous discussion concerning the future of HIV testing and confidentiality in Canada, and to ensure that decisions about HIV testing and confidentiality will be based on a careful consideration of risks and benefits, informed by solid scientific research, that balances an individual's human rights and society's need to maintain public health.

While the *Report* focuses on the issues raised by HIV testing and confidentiality in Canada, a review of the situation in other countries was also undertaken, and the *Final Report* contains numerous references to international documents on HIV testing produced by the World Health Organization and the Joint United Nations Programme on HIV/AIDS, as well as to approaches to HIV testing and confidentiality taken in other countries.

The *Report* has been widely distributed and made available on the Legal Network's website at www.aidslaw.ca. Info sheets summarizing the *Report's* most relevant information are being produced, and other activities aimed at ensuring that the recommendations in the *Report* will be implemented are being undertaken.

HIV Testing and Confidentiality: Final Report is available free of charge (postage and handling fees may apply, however, for requests from outside Canada) from the Canadian HIV/AIDS Clearinghouse. Tel: 613 725-3434; fax: 613 725-9826; email: <aids/sida@cpha.ca>.

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[1] R Jürgens. *HIV Testing and Confidentiality: Final Report*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998 (290 pp, ISBN 1-896735-16-9).

[2] R Jürgens, M Palles. *HIV Testing and Confidentiality: A Discussion Paper*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1997. For a summary of the paper, see the *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 3-7.

HIV/AIDS and the Law: A Resource Manual[1]

Published by the AIDS Law Project and Lawyers for Human Rights in South Africa, this is a comprehensive resource manual on HIV/AIDS and the law in South Africa.

Situating much of its argument around South Africa's *Bill of Rights*, the manual's 13 chapters examine and explain the rights of people with HIV/AIDS in relation to issues such as employment, insurance, health care, the criminal law, and education. The manual is written in plain English, illustrated, and accompanied by a trainers' manual. Although based upon the experience of people with HIV/AIDS in Southern Africa, it will be of value to a far broader audience, including in the so-called developed world: it enunciates fundamental human rights principles that are applicable worldwide, and provides a model for a resource manual on HIV/AIDS and the law that could be duplicated in other countries. The manual has a foreword by Justice Edwin Cameron, the founder of the AIDS Law Project and a contributor to this issue of the *Newsletter*, and an introduction by Susan Timberlake, formerly Human Rights Adviser at UNAIDS.

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[1] *HIV/AIDS and the Law: A Resource Manual*. The AIDS Law Project & Lawyers for Human Rights, 1997 (ISBN 1-86838-166-8). For more information, contact the Coordinator, AIDS Law Project, Private Bag 3, University of the Witwatersrand, South Africa. Tel: (27-11) 403-6918; fax: (27-11) 403-2341; email: <125ma3he@solon.law.wits.ac.za>.

ICASO Publications in the Area of HIV/AIDS and Human Rights

The International Council of AIDS Service Organizations (ICASO) has been actively involved in HIV/AIDS and human rights activities. The following is a brief summary of recent initiatives and publications.

Three-Year Strategic Plan

In June 1998, following extensive discussions with its component networks and organizations, ICASO developed a three-year strategic plan entitled *The ICASO Plan on Human Rights, Social Equity and HIV/AIDS*. The discussions included a formal meeting, the ICASO Inter-Regional Consultation on Human Rights, Social Equity and HIV/AIDS, which was held in Toronto, Canada, in March 1998. The Consultation involved 25 participants from around the world, and observers from agencies such as UNAIDS, the Canadian International Development Agency (CIDA), and the United States Agency for International Development (USAID).

The ICASO Plan contains:

- an analysis of the relationship between HIV/AIDS and human rights;
- a framework for ICASO's future work on human rights and social equity issues, including guiding principles, goals and objectives, and the roles of the ICASO component networks and organizations;
- specific activities in the areas of networking, communications, partnerships, education and advocacy materials, working within the international human rights system, and the use of information databases; and
- specific workplan proposals for the Asia/Pacific Council of AIDS Service Organizations (APCASO), the African Council of AIDS Service Organizations (AfriCASO), and the Latin

American and Caribbean Council of AIDS Service Organizations (LACCASO).

The ICASO Plan is available in English, French, and Spanish from the Central and Regional Secretariats or can be downloaded from the ICASO website.

International Guidelines on HIV/AIDS and Human Rights

In October 1997, ICASO prepared two booklets to assist community-based organizations to make use of the International Guidelines on HIV/AIDS and Human Rights released by UNAIDS.[1] These booklets were reissued in June 1998.

The NGO Summary of the International Guidelines on HIV/AIDS and Human Rights provides a popular summary of the Guidelines, making them more accessible to people in community-based organizations.

An Advocate's Guide to the International Guidelines on HIV/AIDS and Human Rights contains a series of articles on how to use the Guidelines to do advocacy work in the area of HIV/AIDS and human rights, as well as a number of success stories describing how community-based organizations, other non-governmental organizations, and governments have used the Guidelines to bring about positive change.

The NGO Summary and the Advocate's Guide are available in English, French, and Spanish from the Central and Regional Secretariats.

Improving Linkages

In May 1998, ICASO released a document entitled *Improving Linkages between HIV/AIDS Organizations and Human Rights NGOs*. This document describes perspectives from AIDS community-based organizations and human rights NGOs on their work in HIV/AIDS and human rights; obstacles preventing partnerships; and areas of common interest. Recommendations for improving linkages include: development of formal training workshops; integration of HIV/AIDS into existing human rights training; improved communications between the communities; joint project initiatives; and greater integration of the two communities. *Improving Linkages* is available in English from the Central Secretariat.

Information Databases

In May 1998, ICASO released *The Role of Information Databases in HIV/AIDS and Human Rights Work*. This document is a preliminary examination of what information on HIV/AIDS and human rights work already exists, what needs to be collected, how it will be used, who should collect it, how it should be collected, and how it can be disseminated. *The Role of Information Databases* is available in English from the Central Secretariat.

Networking Guide

In early 1997, ICASO produced an *HIV/AIDS Networking Guide*, a comprehensive resource for individuals and organizations who wish to build, strengthen, or sustain a network. The Guide covers a number of topics, including the benefits of networking, the characteristics of a network, a step-by-step guide to building a network, how to deal with change and challenges, how to mobilize resources, the role of email in networking, and governance and staffing issues in formal networks. The Guide is available in English, French, and Spanish from the Central and Regional Secretariats and can be downloaded from the ICASO website.

ICASO's Central Secretariat is at 399 Church Street, 4th Floor, Toronto, ON, Canada M5B 2J6. Tel: 1-416 340-2437 (main reception); fax: 1-416 340-8224; direct phone: 1-416 340-8484 ext 243 (Richard Burzynski) or 221 (Yolanta Cwik); email: icaso@web.net; website: www.web.net/~icaso/icaso.html

The African Council of AIDS Service Organizations (AfriCASO) is at ENDA Tiers Monde, 4, rue Kleber, BP 3370, Dakar, Senegal. Tel: (221) 822-9695 or 823-6617; fax: (221) 823-6615; email: africaso@enda.sn (contact: Bineta Diop or Abdoulaye Diaw).

The Asia/Pacific Council of AIDS Service Organizations (APCASO) is at Kabalikat Ng Pamilyang Pilipino, Room 201, Westwood Condominium, 23 Eisenhower Street, Greenhills 1502 San Juan, Metro Manila, Phillippines. Tel: (63-2) 721-2528, 404 3098;fax: (63-2) 721-0375; email: kablikat@mozcom.com (contact: Malu L Quintos).

The European Council of AIDS Service Organizations (EuroCASO) is at Groupe sida Genève, 17, rue Pierre-Fatio, CH-1204 Geneva, Switzerland. Tel: (41-22) 700-1500; fax: (41-22) 700-1547; email: florian@hivnet.ch (contact: Florian Hübner)

The Latin American and Caribbean Council of AIDS Service Organizations (LACCASO) is at Fundación para el Estudio e Investigación de la Mujer (FEIM), Paraná 135, piso 3, Depto "13", (1017) Buenos Aires, Argentina. Tel: (54 1) 372 2763; fax: (54 1) 375 5977; email: laccaso@ciudad.com.ar (contact: Mabel Bianco).

The North American Council of AIDS Service Organizations (NACASO) is at the National Minority AIDS Council, 1931 NW 13 Street, Washington, DC, USA 20009. Tel: (1-202) 483-6622; fax: (1-202) 483-1135; email: jcolema @nmac.org (contact: Jacqueline Coleman).

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[1] Office of the United Nations High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS. *HIV/AIDS and Human Rights. International Guidelines*. New York and Geneva: United Nations, 1998 (HR/PUB/98/1). See also Guidelines on HIV/AIDS and Human Rights Adopted. *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 1, 45-49.

UPCOMING EVENTS

AIDS Impact – 4th International Conference

The Canadian Psychological Association (CPA) is hosting *AIDS Impact – Biopsychosocial Aspects of HIV Infection* in Ottawa. Involving up to 2000 delegates from all parts of the world, the meeting convenes at the Ottawa Congress Centre from 15 to 18 July 1999.

The theme of this year's conference (previous meetings were held in Brighton (UK), Amsterdam, and Melbourne) is "Connecting a World of Resources" – *AIDS Impact* being designed to connect people to information and expertise in HIV using high technology and global networking. The conference will highlight innovations that contribute positively to developing policy, practice, and planning for the future.

Legal, ethical, and human rights issues raised by HIV/AIDS will feature prominently at the conference, including at the plenary level, in abstract symposia, and in so-called "Hot Topic" discussion sessions, which provide an ideal format in which to debate some of the most controversial issues, such as whether sterile injection equipment should be made available in prisons, how testing policies for pregnant women should be designed, etc.

For more information, visit the conference website at www.aidsimpact.com or contact the AIDS Impact 1999 Secretariat, 151 Slater Street, Suite 205, Ottawa, Ontario, Canada K1P 5H3. Tel: 613 237-2144; fax: 613 237-1674.

GENEVA98: LAW, ETHICS, AND HUMAN RIGHTS

In this special section of the *Newsletter,* made possible by funding received from the Joint United Nations Programme on HIV/AIDS (UNAIDS), we reproduce nine of the most relevant presentations on legal, ethical, and human rights issues raised by HIV/AIDS given at the Geneva98 World AIDS Conference, as well as selected abstracts. With funding from UNAIDS, the *Newsletter* 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 of the *Newsletter.* The goal is to

- increase access to materials on human rights, legal, and ethical issues raised by HIV/AIDS, for individuals and organizations worldwide;
- facilitate networking among individuals and groups active in the area; and
- promote policy and legal responses to HIV/AIDS that respect human rights.

Human Rights and Public Health: An Overview

The HIV/AIDS pandemic has helped to alter the perception that the goals of public health and human rights are incompatible. In this presentation, Sofia Gruskin reinforces the links between human rights and public health. The presentation describes how the responsibilities of governments for health and for respecting, protecting, and fulfilling human rights are enshrined in international human rights covenants, conventions, and declarations. It then refers to the gap between rhetoric and practice and to ongoing violations of the rights of people infected and affected by HIV/AIDS. The presentation explains how a human rights framework can be applied to dealing with public health issues and, specifically, HIV/AIDS. The example of women's reproductive health is used to highlight governmental responsibility for both health and human rights. It concludes with the observation that we must be vigilant in ensuring accountability for what governments are and are not doing.

It is worth recalling that, until recently, the goals of public health and human rights were thought to be fundamentally antagonistic. From the perspective of human rights, there was a deep distrust of measures taken in the name of public health – after all, public health is considered a legitimate justification for governments to use when they restrict rights. From the perspective of public health, it usually seemed that if the two communities ever did interact it was because public health workers were trying to do their job and people working in human rights were trying to stop them. But people in both communities share a deep commitment to ensuring the conditions necessary for human well-being. As well, thanks in large part to the recognition of the importance of respect for human rights in governmental approaches to HIV/AIDS – a recognition that has existed since the beginning of the pandemic – we are beginning to understand more about the relationship between human rights and public health, and about the ways in which working together can be mutually reinforcing.

> Until recently, the goals of public health and human rights were thought to be fundamentally antagonistic.

International human rights law is really about defining what governments can do to us, cannot do to us, and should do for us.

The focus of public health work is primarily on identifying and measuring threats to the health of populations, and developing policies and programs to respond to these conditions, including the assurance of health services and other related services. In human rights the concerns are, broadly speaking, about the relationship between individuals and the state. International human rights law is really about defining what governments can do to us, cannot do to us, and should do for us. For example, governments should not do things like torture people, imprison them arbitrarily, or invade their privacy. But governments should ensure that all people in a society have shelter, food, medical care, and basic education. The concept of human rights has a long history, but the modern human rights movement really dates to the time 50 years ago when the promotion of human rights was set out as one of the purposes and principles of the newly created United Nations (UN).

Human Rights Documents and HIV/AIDS

The key human rights document, and the cornerstone of the modern human rights movement, is the Universal Declaration of Human Rights (UDHR). It is an aspirational document – by governments, for governments – about what rights should exist for all people everywhere. The UDHR was adopted by the UN General Assembly on 10 December 1948, and it celebrated its 50th anniversary in 1998. A number of international human rights treaties further elaborate the rights set out in the UDHR. Each of these documents, from the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights, to the Convention on the Elimination of All Forms of Racial Discrimination, the Convention on the Elimination of All Forms of Discrimination Against Women, and the Convention on the Rights of the Child, lays out legally binding obligations for the governments that sign on to them.

How is health and government responsibility for health codified in these documents? First, the right to the highest attainable standard of physical and mental health appears in one form or another in almost all of them. But even more important, nearly every article of every document can be understood to have clear implications for health. Everything, from the right to information, to association, to social security, and to the benefits of scientific progress and its applications, has clear implications for the work of public health.

None of the human rights treaties specifically mentions HIV or the rights of individuals in the context of HIV/AIDS. But all the international human rights mechanisms responsible for monitoring government action have expressed their commitment to exploring the implications of HIV/AIDS for governmental obligations. And governments themselves, in the political commitments they have made at recent international conferences like the Cairo International Conference on Population and Development and the Beijing Fourth World Conference on Women, have stated their responsibility for ensuring the rights of individuals in the context of HIV/AIDS.

Yet, as we all know all too well, there is a tremendous gap between rhetoric and practice. Violations continue to occur around the world against women, men, and children infected by, affected by, and vulnerable to HIV/AIDS. Violations occur when, for example, people with HIV/AIDS face marginalization and discrimination as well as violations of many of their rights relating to health, education, and social services. People who are affected by HIV/AIDS when their close or extended families, their communities and, more broadly, the structures and services that exist for their benefit are strained by the consequences of the pandemic, face marginalization and stigmatization on the basis of perceived HIV status. They also face violations of many of their rights, including the right to health services, education, and social programs. As for vulnerability to HIV, which is really ultimately about the extent to which we are able to exert control over our lives, the effects of marginalization – particularly as a result of racism, gender-based discrimination, and homophobia – have exacerbated the effects of the pandemic on the lives of individuals around the world.

Responsibilities of Governments

Given the violations that continue to occur in the context of HIV/AIDS, it is useful to consider the specific human rights responsibilities of governments. Governments are responsible for not violating rights directly, but they are also responsible for ensuring the conditions that enable us to realize our rights as fully as possible. It is understood that for every human right, governments have responsibilities at three different levels. They must respect the right, they must protect the right, and they must fulfill the right. As an illustration, consider governmental obligations with respect to the right to education in the context of HIV:

- Respecting the right means that governments cannot violate the right directly. This means the right to education is violated if children are barred from attending school on the basis of their HIV status.
- Protecting the right means that a government has to prevent violations of rights by non-governmental actors, and offer some sort of redress that people know about and can access if a violation does occur. This means, for example, that a government has to ensure that extremist religious groups are not successful when they try to stop adolescents from accessing reproductive-health education.
- Fulfilling the right means that governments have to take all appropriate measures – legislative, administrative, budgetary, judicial, and other – toward fulfilling the right. Thus, if a government fails to provide essential HIV/AIDS prevention education in enough languages and media to be accessible to everyone in the population, this (in and of itself) could be understood to be a violation of the right to education.

Of course, it is clear that resource and other constraints can make it impossible for a government – any government – to immediately and completely fulfill all rights. The human rights machinery acknowledges this, and recognizes that in practical terms a commitment to the right to basic education requires more than just passing a law. It requires financial resources, trained personnel, facilities, textbooks, and other infrastructure, all of which is not going to happen overnight or as soon as a government signs on to a human rights treaty guaranteeing this right. Therefore, attainment of rights is generally understood to be a matter of "progressive realization" – ie, of making steady progress toward a goal. This concept is critical for resource-poor countries that are responsible for striving to attain human rights goals to the maximum extent possible. But it also imposes an obligation on wealthier countries to engage in international assistance and cooperation.

Applying a Human Rights Framework

Let us consider the specific application of a human rights framework to public health. Under specific circumstances, public health workers can impose restrictions on human rights for the benefit of public health. While there are some rights (such as the right to be free from torture or from slavery) that are absolute and can never be taken away, under international human rights law most rights can be legitimately restricted in some circumstances (such as the need to interfere with freedom of movement when instituting quarantine or isolation for a serious communicable disease). But simply justifying the action as necessary for public health is not sufficient. Several criteria have to be met for government actions to be acceptable under international human rights law: the action has to be taken in accordance with the national law; it has to be in the interest of a legitimate objective; it has to be strictly necessary to achieve this goal; it must be the least restrictive alternative; and it can not be imposed in an unreasonable or discriminatory way.

How many young people are infected because they were denied access to information that was considered too sexually explicit for them?

A human rights framework can be useful to identify when public health actions are abusive, whether intentionally or unintentionally. For example, an HIV-prevention strategy that consists of police round-ups and mandatory testing of sex workers raises obvious human rights concerns. There are also more subtle violations. Consider the impact that violations of the right to information have had on the rates of HIV infection in young people around the world. How many young people are infected because they were denied access to information that was considered too sexually explicit for them? The horrible irony is, of course, that they most likely became infected because they were already sexually active.

Recognizing human rights in the design, implementation, and evaluation of health policy can help point the way toward more effective action.

Governments are responsible for making every effort to put policies and programs into place that can reduce the impact of HIV/AIDS.

Recognizing human rights in the design, implementation, and evaluation of health policy can help point the way toward more effective action. This is because human rights can provide a framework within which to identify the civil, political, economic, social, and cultural dimensions of life that are linked to, and can even be determinants of, health status. For example, because the likelihood of people becoming HIV-infected and receiving adequate care is largely influenced by the environment in which they live, a narrow, traditional public health approach focused on the individual and disconnected from a societal context will be of limited effectiveness. Using human rights concepts, one can evaluate the extent to which governments are respecting, protecting, and fulfilling their obligations with respect to all rights (civil, political, economic, social, and cultural), and how this projects itself into the patterns of who is getting infected and what is being done about it.

One Example: Women's Reproductive Health

This point can be illustrated by considering governmental responsibility for women's reproductive health. It is clear that violations of human rights, including systemic gender discrimination, create an environment of increased risk for women's health. In this context, consider the factors that relate to a woman's reproductive health – lack of access to quality services; lack of access to any services at all; or services that are not adequately targeted to respond to her needs – and underlying all this, the impact of gender roles and gender discrimination on both health status and the delivery of services. This underscores the importance of human rights because the gaps and the inequalities in services and structures become really apparent when one looks at how the social roles that construct male and female identity play out at the policy and program level in terms of reproductive health research, policy, and service delivery.

Consider the measures that have generally been understood to be critical to improving women's reproductive health. Traditional public health focused on the need for information, education, counseling, contraception, and access to quality services. These things were, and still are, considered central to improving women's reproductive health. But even if these services are available, a woman has to be able to decide when and how she is going to access them – which means she has to have the ability to control and make decisions about her life. Human rights are meant to directly address the societal context – in this case, the context that hinders or empowers a woman's ability to make and carry out the free and informed choices necessary for her reproductive health.

With this example in mind, and looking at these issues from the perspective of governmental responsibility, the language of the Cairo Conference on Population and the Beijing Fourth World Conference on Women becomes really useful. Both Cairo and Beijing explicitly recognized the need for a combined public health/human rights approach. They also recognized that human rights status plays a major role in determining reproductive health. The fact that this explicit recognition exists in the Cairo and Beijing documents is particularly useful because the language and the concepts that are found in these documents represent the consensus and political commitment of governments around the world. This means that we can not only access the language and concepts but can also put them to use.

Conclusion

With respect to HIV/AIDS, governmental commitments, both legal and political, are there. This is an important first step, but discrimination against people with HIV/AIDS and people considered at high risk of infection continues to occur in new and different ways. This is true in prevention, in care, and in research. We must be far more vigilant not only in monitoring what is happening, but also in ensuring accountability for what governments are and, more important, are not doing.

Human rights belong to everyone. Exactly what this means with respect to their interpretation, advocacy, and defence is constantly evolving. The world of human rights and AIDS floats between two extremes. On the one hand, there is the more legalistic approach: human rights are about the strict interpretation of international law. On the other, there is the more activist approach: human rights are everything that people need to overcome a crisis, such as AIDS. The legalistic approach has the merit of maintaining credibility with governments and institutions of power. The activist approach ensures that rights remain relevant to our changing world. It is by maintaining the dialogue between these two approaches that the usefulness of human rights for action will be recognized, and that human rights will take their rightful place in our lives.

– presented by Sofia Gruskin

Sofia Gruskin, JD, MIA, is the Director of the Human Rights Program at the François-Xavier Bagnoud Center for Health and Human Rights, Harvard School of Public Health, Boston, Massachusetts. Sofia can be reached at <sgruskin@hsph.harvard.edu>.

Thirty Million and Counting: The Urgent Need to Move from Policy to Comprehensive Interventions

There are many obstacles to implementing an effective response to the HIV/AIDS epidemic in the Third World. In his presentation at the Conference, Mark Heywood, of the AIDS Law Project of South Africa, discusses the failure of governments to address human rights concerns and provides examples of how government actions sometimes directly violate human rights. The presentation examines the challenges for effective activism in the Third World. It stresses the need for human rights and AIDS activists to go beyond calling for more access to treatments and to advocate for solutions to the severe economic and social problems that plague the region and that feed the epidemic. The presentation concludes that people with HIV/AIDS must speak up for their rights; that human rights NGOs and other non-HIV/AIDS organizations must join the fight against HIV/AIDS; and that the time has come to put into practice the many policy statements, codes, and charters that have been drafted on HIV/AIDS and human rights.

The struggle for human rights is most effectively conducted at a local level. However, the longer-term effectiveness of the work of local human rights and AIDS activists is influenced by international politics and international policymakers. The 1998 World AIDS Conference is an appropriate forum to raise a number of issues that relate primarily to national and international governance, but that also have a direct bearing on the short-, medium-, and long-term impact of our efforts to combat the epidemic. This presentation focuses on Africa. This is not to suggest that human rights abuses are not a problem in the industrialized world.

> "All human beings are born free and equal in dignity and rights," according to the Universal Declaration of Human Rights. This assertion is not true.

Free and Equal?

"All human beings are born free and equal in dignity and rights," according to the Universal Declaration of Human Rights.[1] This assertion is not true. The United Nations Joint Programme on HIV/AIDS (UNAIDS) estimates that 800,000 children in Africa have HIV or AIDS.[2] This is 87 percent of the global total of infected children. More than 12 million women have HIV in Africa. More than 10 million men. These people do not have equal rights to dignity or life. They do not have the potential to assume these rights. Indeed, as UNAIDS wrote in its report of December 1997, it can be assumed that most of the people presently infected with HIV in sub-Saharan Africa will die prematurely.[3]

> After several decades of slow improvements in rights and living conditions, large parts of the developing world are beginning to witness rapid reversals.

To date, the international human rights covenants have not provided protection to people with HIV/AIDS. The International Covenant on Economic, Social and Cultural Rights (ICESCR) requires governments to "progressively realize" ("to the maximum of their available resources") socioeconomic rights such as improved access to housing and health.[4] But the pandemic nature of AIDS is making it more difficult to do this. After several decades of slow improvements in rights and living conditions, large parts of the developing world – perhaps it would be more appropriate to call it the non-developing world – are beginning to witness rapid reverses.

Less Free and Less Equal

The epidemic has already set off what the United Nations Development Programme (UNDP) describes as "a cascade of economic and social disintegration and poverty" in Africa. The 1997 UNDP Human Development Report provides scientifically verified evidence of this:

- Infant mortality is rising again in many countries.
- In countries such as Botswana, Zimbabwe, and Malawi, life expectancy has already dropped dramatically.
- Gender inequality and child labour are increasing as the burden of care

> falls on the women and children in the family of an infected person.[5]

All these issues are matters of human rights, particularly when declines in our part of the world are grotesquely inverted as advances in the North. This should be setting off alarms in every United Nations (UN) agency, development NGO and human rights organization in the world (to say nothing of governments). AIDS workers are seeking not the artificial introduction of a human rights angle into the work of these organizations, but rather a recognition of the impact of HIV and a sensitivity to the human rights dimensions of the epidemic. For example, a recent evaluation of a women's empowerment project in Tanzania that aims to reduce infant mortality found that by 1998 HIV/AIDS had not been factored into its work.[6] This is despite the fact that the gains of the work of the last decade on infant mortality will soon be threatened.

The recognition that human rights are intricately linked to this epidemic and should guide our response is one of the themes of this Conference. But it has come very late in our attempts to impede the spread of HIV. Even now, this human rights link is not widely understood and is resisted by many policymakers because it is considered political.

Human Rights

Human rights are, and are not, political. They become political when they are ignored or abused. It is an internationally accepted principle that human rights, like law, should guide our society. Human rights are supposed to establish a legal and moral imperative that should infuse many of our social interactions and inform our strategic planning and interventions. But with respect to HIV/AIDS, there is also a very strong public health rationale for incorporating a human rights dimension in our response to the epidemic because respect for the rights of people with HIV/AIDS facilitates effective prevention. (The reverse is also true: effective prevention facilitates respect for the rights of people with HIV/AIDS.) This point is important to bear in mind, considering that the volume of human rights abuses is mounting.

There are three aspects to the human rights dimension of the AIDS epidemic that I will discuss here: human rights omissions, the role of governments, and civil and political rights.

Human Rights Omissions

Human rights omissions – ie, the failure of governmental and intergovernmental organizations to identify and address rights – are at the root of the endemic vulnerability of Third World populations. They provide reasons for the emerging and explosive epidemics that threaten parts of the world such as China, India, and Africa.[7] Tragically, the UN does not have power to compel governments to progressively realize socio-economic rights (particularly with respect to housing, access to health care, water, etc), the lack of which has left populations vulnerable to corrupt governments and economic forces that place them perpetually in poverty.

Poverty is one of the main causes of vulnerability to HIV. UNAIDS has pointed out in its Strategic Plan that

> in the context of people's lives, many of our key AIDS messages and services may be irrelevant. ... Billions of men, women and children live in a societal context in which they would not be able to exercise prevention and care options even if these were available to them.[8]

The problems HIV/AIDS workers experience with effecting behaviour change in relation to HIV are often the same as the problems experienced with effecting behaviour change on other issues. For example, a researcher in Tanzania found that although they know about the risk associated with giving infants unsterilized water, many women still use unsterilized water because of the arduous nature of finding and collecting wood.[9] But it is one thing to point this out; it is another to address its implications.

Role of Governments

Governments could potentially be the key that unlocks and facilitates effective HIV prevention, but often they are the cause of the failure of HIV prevention.

The Nigerian military dictatorship is frequently (albeit ineffectually) condemned for human rights abuses. However, there is a continuum between the hanging of the Nigerian writer Ken Sarawiwa and the government's response to HIV/AIDS.[10] In Nigeria, which may already be the country most severely affected by AIDS in Africa,[11] the draft National AIDS Plan is effectively a secret document. Participants at a recent seminar in Abuja, the capital of Nigeria, complained about being refused access to the draft policy.[12]

Recently, the government has instituted mandatory testing of patients in teaching and general hospitals.[13] In 1996 the Governor of a Nigerian State called for the arrest and detention of all people with HIV/AIDS. [14]

Many human rights activists ask why the UN and the United States, which saw fit to intervene militarily in the Middle East to "defend" the population of a country from dictatorship, do not look at ways of increasing pressure on Nigeria. Instead, United States President Bill Clinton sanctioned the Nigerian regime by visiting Lagos recently on a tour of Africa, during which he made no mention of AIDS.

Civil and Political Rights

AIDS still attracts widespread and sometimes horrific violations of political and civil rights. This kind of abuse stems from actions within our institutions – ie, prisons, workplaces, hospitals and schools – and irrational actions of communities. The targets of these abuses are, disproportionately, women. There is a relationship between these violations and the failure of governments to make significant progress on at least some of the key determinants of social equity.

Many African communities still practise customs and rituals that create vulnerability to HIV but will only disappear when there is more equal access to education, electricity, jobs, and water, as well as civil and political rights. Consider the following examples:

- The government of Côte d'Ivoire has recently passed a law against female genital mutilation. But, as many people have pointed out, policy and law alone do not change practice.
- In Zambia, the custom of ritual cleansing, where a woman is required to sleep with her deceased husband's brother after he dies, is still widely practised.

So what should AIDS activists be doing?

Access to Treatment

In attempting to define what AIDS activists should be doing, we must first seriously question the way in which demands for treatment are being made an all-too-easy theme to rally AIDS activists and the human rights movement. There is a danger that governments in underdeveloped countries, who already resist taking ownership of a national AIDS strategy, will see this as a convenient opportunity to shift responsibility once again. Instead of facilitating a holistic response, they will join the chorus calling for antiretroviral therapy. They may also see this call as an easy escape from their obligations to address the causes of vulnerability and infection. Indeed, "affordability" and the "greed of drug companies" (two of the key slogans of ACT-UP Paris) may turn out not to be the primary obstacles to treatment. The real problem is that social conditions will make compliance with a complicated and Eurocentric regimen almost impossible in countries where most people with HIV/AIDS cannot read, do not have enough to eat, and do not have watches, nearby clinics, or clean water.[15] That is why the demands of AIDS activists must also be for the rapid realization (without caveat) of the unavoidable necessities of life in the late twentieth century: Clean water for all! Electricity for all! Open and accountable government!

This argument should not be misunderstood. It is important to demand treatment. Human rights activists should demand emergency implementation of scientific findings relevant to the Third World. Despite what we now know of the efficacy and cost-effectiveness of a short course of AZT for pregnant women, there are few signs that any government will make this treatment widely available. But these demands must be made side-by-side with demands for the renegotiation of Third World debt and a First World–financed "Marshall Plan" that will lead to the beginning of quantifiable improvements in the conditions that have caused this epidemic and will cause future epidemics. These calls may be considered naïve. But what is the alternative? The alternative is to accept the status quo and thus accept that HIV prevention will never be very effective, and that HIV and AIDS will be generalized and fatal in developing nations for the foreseeable future.

Obstacles to Effective Activism

It is useful to identify some of the obstacles to effective activism. Most important is the climate that has been created by discrimination. In the developing world, there is enormous fear of disclosure or even association with people with HIV/AIDS. Linked to this is the failure of national AIDS plans to create an awareness of the social dimensions of AIDS. This helps explain the failure of trade unions, women's organizations, civic associations, churches, and others to join those working on HIV/AIDS in this struggle.

As well, there is the very nature of activism, which is seen as confrontational (as it should be) and is not regarded as a legitimate part of HIV prevention. This makes it difficult for activist organizations to secure funding from government or the private sector. It also makes sustainability enormously difficult.

A Sense of Urgency

There needs to be a far greater sense of urgency. Why are governments not being called to account for their failures? It is because the First World and, unfortunately, affected populations in the Third World, are complacent about the death of poor and marginalized people in the world. In Africa, for example, people are expected and expect to suffer diseases, famines, and epidemics. It is considered natural that in Africa people die young. There seems to be an attitude that Africans are dispensable.

The former South African policy of apartheid encouraged a disregard for black life and potential amongst most white people, including many of the so-called liberal opponents of apartheid. Despite the change of government, this attitude still exists. It also extends far beyond South Africa. It originated in enduring colonial attitudes about the dispensability and non-comparability of life in "the tropics." However, until the emergence of the black consciousness movement in the 1970s, this attitude was also embodied in the oppressed population. Black consciousness leaders did an enormous amount of work to restore a sense of pride and rights to black people.

Africa needs a similar movement. People with HIV/AIDS and affected people in Africa (and Asia) are generally resigned and silent about their own needs and demands. Until the present mind-set changes and all people regard preventable illness and mortality to be as unacceptable and avoidable in the Third World as it is in the First World, our human rights will continue to be truncated from cradle to early grave.

This realization partly underlies the recent commitment of African leaders to an "African Renaissance." However, a word of caution is necessary here as well. Up to now, the proponents of the African Renaissance, including President Nelson Mandela, have made no reference to the impact that AIDS is having on society. The African Renaissance is seen primarily as an economic regeneration that will lead to a social revival. If this view goes unchallenged, there is a real danger of further human rights violations. Pre-employment HIV testing, which is already on the increase, will be sanctioned on the grounds that it is fair because a healthy and productive work force is necessary for economic competitiveness. Decisions on resource allocation may favour short-term development over effective HIV prevention and providing access to treatments and care for people with HIV/AIDS, all of which is costly.

Definitions of Success

Human rights activists should reassess their definitions of "success" and "community mobilization." In the last 15 years, there have been many important community campaigns, especially those organized by gay and lesbian organizations and individuals in the developed world. There are isolated and heroic examples of individual or community mobilization in the developing world.[16] Important principles have been fought for and established in developed nations: the right to privacy, the right to informed consent, and the right to access treatment. However, globally, activists have not succeeded in mobilizing around AIDS. A much broader spectrum of players than just AIDS activists must now be mobilized. Generally, AIDS activists still operate on the margins, rather than at the centre, of social concerns.

Our successes may be numerous, but they are not enough. Human rights and AIDS activists fight primarily to protect and improve the life of the individual, but we also aspire to have an influence on the lives of all people who are vulnerable to discrimination. The latter is not happening. Broad policy statements, codes, and charters have been drafted that embrace millions of people; but they are not being operationalized and often have little impact. Consequently, in the developing world and parts of the industrialized world the quality of life of people with HIV/AIDS is getting worse.

This is the question that should be posed to human rights organizations, governments, and many UN agencies: Are you sleeping? Can you go on doing nothing?

Conclusion

At gatherings like the World AIDS Conference, it seems to be a tradition to turn to our writers to try to capture our dilemmas. Yesterday, a poem by John Donne was cited by a South African epidemiologist, Quarraisha Abdool Karim, to the effect that "No man is an island." This presentation will end with an unlikely quotation from Samuel Beckett's *Waiting for Godot*, in which one of the two central characters asks:

> Was I sleeping, while the others suffered? I am sleeping now? Tomorrow, when I wake, or think I do, what shall I say of today? … At me too someone is looking, of me too someone is saying, he is sleeping, he knows nothing, let him sleep on. I can't go on!

Continued from previous page.

This is the question that should be posed to human rights organizations, governments, and many UN agencies: Are you sleeping? Can you go on doing nothing?

– presented by Mark Heywood

Mark Heywood is Head of the AIDS Law Project at the Centre for Applied Legal Studies, University of the Witwatersrand in Johannesburg, South Africa. Mark can be reached at <125ma3he@solon.law.wits.ac.za>.

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[1] UNAIDS. Universal Declaration of Human Rights. An Activists Guide to the UN Human Rights Machinery. UNAIDS, 1997, at 27.

[2] UNAIDS. Global Update on the HIV/AIDS Epidemic, June 1998; World Bank. Confronting AIDS, Public Priorities in a Global Epidemic. Policy Research Report, 1997.

[3] UNAIDS. AIDS epidemic update, December 1997.

[4] UNAIDS: An Activists Guide, at 43.

[5] UNDP. Human Development Report, 1997.

[6] F Young. Presentation to South African Department of Health Seminar on HIV/AIDS and Development, June 1998.

[7] QA Karrim. The Epidemiology of HIV Infection: New and Emerging Epidemics, Presentation to Plenary, 12th World AIDS Conference, 30 June 1998.

[8] UNAIDS Strategic Plan, 1996-2000 (Revised December 1995). Cited by S Timberlake. UNAIDS: Human Rights, Ethics and Law. *Health and Human Rights*, 3:1, 1998.

[9] Young, supra, note 6.

[10] Ken Sarawiwa was a Nigerian writer who campaigned for greater autonomy and control for the Oguni people in Nigeria concerning the oil wealth in their region. He also attempted to highlight the environmental and human damage being caused by oil companies. In 1996 he was arrested and summarily hanged by the Nigerian authorities, together with six of his comrades.

[11] UNAIDS/WHO. Report on the Global HIV/AIDS Epidemic, June 1998, at 10-11.

[12] Top Secret! Nigeria's AIDS Policy Still at the Printers. *AIDS Action Alert*, June 1998, at 1.

[13] Ibid. Sly Testing for HIV Unethical.

[14] *Business Day* (South Africa), 30 September 1996.

[15] G Sikipa. Compliance Issues in Developing Country Cultures, paper presented to 12th World AIDS Conference, June 1998.

[16] During an NGO networking meeting held shortly prior to the 12th World AIDS Conference, 1998, an account was given of efforts to assassinate and maim AIDS educators working with sex workers in El Salvador. Courageous interventions were also reported from Nicaragua, Israel, and India.

Creation of an Enabling and Gender-Just Legal Environment as a Prevention Strategy for HIV/AIDS among Women in India

In India, the economic, social, and legal inequalities of women make them particularly vulnerable to HIV infection. In her presentation to the Conference, Dr Mandeep Dhaliwal, of the Lawyers Collective HIV/AIDS Unit, examines these inequalities and then focuses on the current legal status of women in India. The presentation explains how this status contributes to women's vulnerability. The presentation argues that we need to move beyond programs such as condom distribution and reproductive-health interventions to address broader societal issues such as gender inequality. It identifies a series of legal and ethical issues that have arisen for women in the context of HIV/AIDS and that need to be addressed. Finally, the presentation proposes a number of legal reforms that would reduce women's vulnerability, thereby empowering them to protect themselves from the spread of HIV infection.

Introduction

The Lawyers Collective, a non-governmental organization, is one of the very few public interest groups of lawyers in India. Since its founding in 1981 by leading lawyers Anand Grover and Indira Jaising, the Collective has fought for the rights of the disadvantaged in society. The HIV/AIDS work of the Lawyers Collective has included two important cases. The first HIV/AIDS case to enter the courts in India was that of Dominic D'Souza.[1] Under the Goa Public Health Amendment Act of 1986, Dominic, a voluntary blood donor, was incarcerated in a TB sanatorium when his unit of blood tested positive for HIV. The Collective successfully gained his release, only to lose Dominic to the virus a few years later. His spirited commitment to justice and equality for people with HIV/AIDS continues to inform our work.

> "I live in the hope of a world that will be free not only of disease but of fear and discrimination."
>
> *– Dominic D'Souza, late HIV/AIDS activist*

The second case was that of a public-sector employee, MX, who was thrown out of his job because he was found to be HIV-positive during medical fitness tests.[2] Orders for non-publication of identity were sought and granted, with the result that the litigant's rights to access justice and to privacy were recognized. In a landmark judgment, the Bombay High Court reinstated MX

What is the purpose of handing out condoms to women if they have no power within a sexual relationship to negotiate their use?

to his job with full payment of back wages. These cases are reflective of the substantive body of work of the Lawyers Collective on HIV/AIDS-related legal and ethical issues over the last seventeen years.

Vulnerability and Empowerment

Seventeen years after the start of the HIV/AIDS epidemic, we continue to approach women's interventions at the micro level – ie, condom distribution and reproductive health interventions. These interventions are crucial, but by themselves have proven to be insufficient in the face of HIV/AIDS and its significantly disproportionate impact on women. What is the purpose of handing out condoms to women if they have no power within a sexual relationship to negotiate their use? I submit that we must also examine issues at the macro level – ie, at the level of broad social issues, such as gender, that impact on the overall vulnerability of women to HIV infection. We must then intervene at this macro level to support and facilitate the success of the interventions at the micro level.

Before we can discuss the legal status of women, we must examine the relationship between human rights and the law, and the role of the law in terms of empowerment. There needs to be a culture of rights. Human rights need to be a part of our language. But today, in fact, in the Indian context and in the context of the developing world, there exists a dramatic gap between the identification and existence of human rights at the grassroots level and the promotion and protection of human rights. This is where the partnership between human rights and the law comes to the fore. Domestic law – ie, a supportive legal framework – seeks to bridge this gap and empower the individual (man, woman or child) to assert and vindicate their rights.

Aspects of Vulnerability

According to the latest UNAIDS figures,[3] there are over four million people with HIV/AIDS in India, over 25 percent of whom are women. In India, when it comes to women and HIV/AIDS, even the "informed" policymakers and activists make the mistake of targeting all their well-meaning interventions at sex workers. Recent surveillance reports from the National AIDS Control Organisation, Government of India, indicate that nationally HIV infection is rising among pregnant women visiting antenatal clinics and that the primary mode of transmission remains heterosexual (at 74.15 percent).[4] Clearly, HIV infection has crossed over into the mainstream population.

It is now well established that certain populations are more vulnerable to contracting HIV infection; women are one such group. Vulnerability is influenced by a host of factors – biological, economic, social, cultural, and legal. In turn, all of these factors have an impact on women's access to services, resources, and information.

There needs to be a culture of rights. Human rights need to be a part of our language.

Biologically, there is more likelihood of HIV infection passing from a man to a woman in unprotected sexual relations than from a woman to a man. The health care of women is virtually neglected except, marginally, in the reproductive context.

Economically, women have less access to the job market and earn lower wages than men for the same work. In the workplace the status of women is lower than that of men. For the most part, women are financially dependent on men. In most households, men are the decision-makers. Large numbers of women are subject to mental, emotional, and physical cruelty. The social and cultural constructs of Indian society are such that women are considered to be subordinate. An example of this is our age-old Indian tradition of *pati parmeshwar*, which often manifests itself as women feeding the men and children first before they eat the remaining scraps.

Vulnerability Arising from the Legal Status of Women

Personal law is the type of law that impacts largely on women in India. Personal law evolved historically and politically during the Mughal Empire. It was perpetuated during British rule in India and continues to exist in modern-day India. Personal law, applicable to people on the basis of their religion, caste, and sect, is fundamentally premised

In India, the legal status of women in practically all spheres of law is subordinate to that of men on the basis of profound gender discrimination.

on stark gender biases. In India today, it is the area of law commonly referred to as family law.

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

There is no legally defined age of consent to sexual intercourse. However, under section 376 of the Indian Penal Code, sex with a minor under the age of sixteen constitutes rape. If the minor concerned is the wife of the other partner, then the age is fifteen. What is shocking is that for women who are fifteen years of age or older, the law in India does not recognize marital rape as an offence. In the case of forcible sex, the most a wife can do is sue for divorce on the ground of cruelty. This ground is not available to Christian women under the Indian Divorce Act. Christian women can divorce if they prove two grounds – adultery and one other ground. Christian men can obtain a divorce if they prove just one ground. Muslim men can divorce by simply pronouncing triple *talak* and can have up to four wives.

Though the Child Marriage Restraint Act outlaws child marriage, the Act is often rendered ineffective. Various marriage laws allow minors to be married with the consent of their parents or guardians. Except in the state of Goa, there is no law governing the distribution of matrimonial property. Women are dependent on their husbands for maintenance. Upon divorce, women are given a pittance of a sum as settlement; as a result, they end up considerably poorer. Even the Criminal Procedure Code does not give women more than 500 rupees (the equivalent of $US12-13) per month as maintenance. As a result, even in a case of marital discord involving cruelty, divorce is usually the last option and women continue to suffer in the confines of disastrous and even deadly marriages.

HIV/AIDS-Related Legal and Ethical Issues for Women

The following are examples of issues that have arisen for women in the context of HIV/AIDS in India:

- Should a person be obliged to disclose their serostatus to the respective partner at the time of marriage? Is non-disclosure tantamount to fraud, thus vitiating the consent to the marriage?
- Does refusal to consummate the marriage because the partner is HIV-positive amount to the willful refusal of sex? Does this constitute cruelty?
- Does insistence by the HIV-positive partner to have sex constitute cruelty?
- Can HIV/AIDS be classed as a venereal disease, and thus constitute a valid ground for divorce?
- What rights does a woman have to matrimonial property after the death of her HIV-positive partner who may also have infected her?
- Upon the death of her partner, is an HIV-positive woman entitled to custody of their child?

Legal Strategies for the Empowerment of Women

The Constitution of India, in its glorious preamble, guarantees all its citizens equality before the law regardless of sex. It is evident from the examples and issues mentioned in this presentation that the law in India, particularly personal law, denies this equality to women. Furthermore, this gross inequality denies women the autonomy necessary to protect themselves from being infected by HIV. This inequality can only be rectified through the establishment of a gender-just legal environment.

Now that we have identified the problem, let us look at possible solutions:

- The general strategy for creating a gender-just legal environment is that existing personal laws should be replaced by a gender-just civil code.
- Legal literacy for women must be encouraged.
- There should be free legal assistance for women, including

exemption from court fees.
- Legal procedures should be time-limited, with mechanisms for monitoring and evaluation.
- There should be community property during and after marriage (including common law marriages).
- Inheritance laws should be changed to ensure that male and female heirs share equally. This is particularly important for women since almost three-quarters of AIDS cases in India are among males.[5]
- Existing presumptions that the father is the natural guardian should be eliminated. It should be recognized that both parents are the natural guardians of the child, in and out of wedlock.
- Laws concerning maintenance should be substantively and procedurally changed to ensure adequate and sustained maintenance.
- The offence of adultery should be completely eliminated since it is based on the assumption that the wife is the chattel of the husband.
- Criminal and civil remedies for violence against women must be instituted.
- Positive laws on domestic violence and child sexual abuse must be developed.[6]

Internationally, it is now well established that protecting and promoting the rights of marginalized populations is vital to preventing the further spread of the HIV/AIDS epidemic. Justice Michael Kirby of the High Court of Australia has described the paradox of HIV/AIDS as follows:

> Paradoxically enough, the only way in which we will deal effectively with the problem of the rapid spread of this epidemic is by respecting and protecting the rights of those already exposed to the virus and those most at risk.[7]

The laws that contribute to the marginalization of women must be repealed or reformed so as to empower women and to bring them onto a more level playing field. It is only then that women will be empowered to protect themselves from contracting HIV infection.

Conclusion

In the Indian context, we must mobilize civil society – ie, the numerous women's groups who are strangely silent and inactive on the issues relating to HIV/AIDS and women. We must open our hearts and minds in order to bridge gaps at many levels. We must leave our provincial moralities at home and bridge the gap between women like us and women like them. We must all, men and women alike, seek to bridge the gaps that exist between men and women in society. For only then can we work together to endeavour to bridge the gap between the existence of women's rights and the basic dignity of women, and the respect and enforcement of these rights and dignity at all levels.

– presented by Mandeep Dhaliwal

Dr Mandeep Dhaliwal is a physician and a lawyer. She is the Co-ordinator of the Lawyers Collective HIV/AIDS Unit, a project supported by the European Commission. The Lawyers Collective HIV/AIDS Unit provides legal aid, advice, and support to those affected by HIV/AIDS. The Unit also undertakes capacity-building and advocacy activities on legal and ethical issues arising out of the HIV/AIDS epidemic in India. Mandeep can be reached at <lawyers@bom2.vsnl.net.in>.

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[1] *Lucy R D'Souza* v *State of Goa*, [1990] Mh LJ 713, Bombay High Court, India.

[2] *MX* v *ZY AIR*, 1997 Bom 406.

[3] Joint United Nations Programme on HIV/AIDS (UNAIDS)/World Health Organization (WHO) Report on the Global Epidemic. Geneva, Switzerland: 1998.

[4] National AIDS Control Organization, Ministry of Health and Family Welfare, Government of India, Country Scenario, 1997-1998: 19.

[5] Ibid at 18.

[6] I Jaising (ed). *Justice for Women: Personal Laws, Women's Rights and Law Reform*, 1996.

[7] M Kirby. Aids and Law. *Daedalus*, Summer 1989: Living with AIDS Part II.

A Human Rights Approach to Reducing Women's Vulnerability to HIV/AIDS

Human rights law and the international human rights machinery are powerful tools that can be harnessed to address the social, political, and economic factors that contribute to women's vulnerability. In this presentation to the Conference, Daniel Whelan reports on the results of a study of the extent to which four United Nations human rights treaty-monitoring bodies have addressed HIV/AIDS as a human rights concern. The presentation analyzes the overall trends of the treaty-monitoring bodies' assessment of HIV/AIDS. It then examines the content of the formal reports issued by the treaty-monitoring bodies. Finally, the presentation evaluates these findings from a gender perspective. The presentation points out that when the UN bodies have addressed HIV/AIDS issues specific to women, the emphasis has been on ensuring that women have access to information and services rather than on the underlying causes of women's vulnerability. The presentation concludes that there is a need to work more closely with the treaty-monitoring bodies to get them to hold governments accountable for providing effective HIV prevention and care, especially for women and adolescent girls.

> Human rights law and the institutions and standards of the global human rights regime provide a powerful set of tools that can be used to address the social, economic, and political context of women's vulnerability.

Introduction

A wide range of approaches to addressing the gender-related determinants of vulnerability to HIV/AIDS is needed. A recent review of research and programs on gender and HIV/AIDS showed that some significant steps have been taken to address the constellation of economic, social, cultural, and political factors that influence women's vulnerability. Most interventions have been designed within the frameworks of public health and economic and social development.

While there have been isolated success stories, the gap remains between what we know about the nature of vulnerability and what we are doing to address it. So the question becomes: How can the protection and promotion of human rights strengthen the public health and development responses to HIV/AIDS, and how can a human rights approach to reducing vulnerability be used?

Human rights law and the institutions and standards of the global human rights regime provide a powerful set of tools that can be used to address the social, economic, and political context of women's vulnerability. Human rights are an internationally recognized set of norms and standards for ensuring human development, well-being, and dignity. These principles have been codified in international law in the form of treaties. Virtually every country in the world has chosen to be bound by the terms of at least one of the six major human rights treaties. The effect of these treaties is to create specific obligations on the part of governments to protect, promote, and fulfill human rights, and to create a monitoring system to measure compliance. These legal obligations and mechanisms of accountability provide a critical opportunity for us to place pressure on governments to enact the policy reforms and allocate the resources necessary to reduce women's vulnerability to HIV/AIDS. That is what makes this approach so compelling.

> The first element of a human rights response is the recognition that violations of civil, political, economic and social rights constitute the roots of vulnerability to HIV/AIDS.to address the social, economic, and political context of women's vulnerability.

The first element of a human rights response is the recognition that violations of civil, political, economic, and social rights constitute the roots of vulnerability to HIV/AIDS. We need to characterize these realities as human rights violations, not just as "the way things are." Second, those of us who conduct research on HIV/AIDS need to analyze what we already know about the determinants of vulnerability with reference to human rights. For example, we know that women's vulnerability to HIV and the impact of AIDS is fostered by their unequal access to key resources such as employment, education, training, credit, ownership, and inheritance. Which human rights, if fully realized, would alleviate this unequal access? Finally, we need to understand how the international human rights system works, and how we can use its language and mechanisms of accountability to advocate for policies and programs to reduce women's vulnerability.

Need for the Study

Under the auspices of the United Nations, there are six major human rights treaties whose provisions include a monitoring system of reporting obligations and a committee to review country reports. Each treaty requires participating states to submit periodic reports to its monitoring body. The reports must address governments' progress in implementing the provisions of the treaty. Each treaty specifies the nature and content of the information provided by governments. Once a report has been reviewed by the committee, there is a face-to-face session between the committee and government representatives. In those sessions, the committee provides comments, asks clarifying questions, and makes recommendations to the state. These "Concluding Observations and Recommendations" are then made public by the United Nations.

In recent years, four of these committees have also allowed non-governmental organizations (NGOs) to submit alternate (sometimes called "shadow") reports at a special session of the committee. This opening provides HIV/AIDS-related NGOs with a unique opportunity to bring important information to the attention of a committee – information that is not likely to be included in a government's report on its own progress.

Description of the Study

In an effort to better understand how the international human rights monitoring system has addressed HIV/AIDS as a human rights concern, I reviewed 211 "Concluding Observations and Recommendations" delivered by four of the six monitoring bodies: the Human Rights Committee (HRC), the monitoring body for the International Covenant on Civil and Political Rights; the Committee on Economic, Social and Cultural Rights (CESCR); the Committee on the Elimination of Discrimination against Women (CEDAW); and the Committee on the Rights of the Child (CRC). This sample covers Concluding Observations issued to developing-country governments from January 1993 through December 1997. These documents are publicly available on the Internet.

It is important to note that the frequency of references to HIV/AIDS in Concluding Observations does not in itself tell us all that much about how the treaty-monitoring bodies have been addressing HIV/AIDS issues from a human rights perspective. The main reason for this is that there are no treaties dealing with HIV/AIDS specifically and little jurisprudence from the committees themselves. Analysis of the content of the Concluding Observations is required to reveal the level of sophistication with which treaty-monitoring bodies have interpreted existing human rights obligations as they relate to HIV/AIDS.

Research Results

Of the 211 Concluding Observations that were reviewed, 50 (24 percent) mentioned HIV/AIDS at least once. Table 1 breaks down this total by treaty-monitoring body. It is interesting to note that 55 percent of the Concluding Observations issued by CEDAW mentioned HIV/AIDS. At the other end of the spectrum, in only one of the 59 Concluding Observations issued by the HRC was HIV/AIDS mentioned.

As for the frequency of references to HIV/AIDS in Concluding Observations across treaty-monitoring bodies, the data show that there has been an upward trend from no references in 1993 to 15 in 1997. (There was a drop in 1996, but analysis revealed that this corresponded to an overall decrease in the baseline number of Concluding Observations issued that year.) Overall, this trend suggests that the treaty-monitoring bodies have begun a process of regularly addressing HIV/AIDS as a critical human rights issue.

Let me turn now to the content of the references to HIV/AIDS made by the committees. Among the 50 Concluding Observations that mentioned HIV/AIDS, there were 104 distinct "citations," meaning that, on average, each Concluding Observations mentioned HIV/AIDS twice.

TABLE 1. MENTION OF HIV/AIDS IN CONCLUDING OBSERVATIONS

TREATY- MONITORING BODY	# COs REVIEWED	# MENTIONING HIV/AIDS	PERCENT MENTIONING HIV/AIDS
HRC	59	1	2 percent
CESCR	44	8	18 percent
CEDAW	45	25	55 percent
CRC	63	16	25 percent
TOTAL	211	50	24 percent

Of the 104 citations, 45 (43 percent) were in the form of comments issued by a treaty-monitoring body. Another 23 (22 percent) were in the form of questions posed by treaty-monitoring bodies to government representatives.

The remaining 36 citations (35 percent) were in the form of what I would term "directive statements" or "recommendations" made by treaty-monitoring bodies to government representatives. These types of citations represent the expectations that treaty-monitoring bodies have of governments. These expectations fall within the treaty-monitoring bodies' mandate as monitors of how governments implement a human rights treaty. The balance of this analysis will focus on these types of citations found through the research.

Analysis of Directive Citations

The directive citations fall within three general categories that will be familiar to those working on HIV/AIDS from a public health perspective. Fifteen (43 percent) of these citations focused on the need for a government to adopt or strengthen certain aspects of its HIV/AIDS prevention program. The vast majority of these citations focused specifically on the obligations of governments to provide HIV/AIDS-related information, education, and services to people in need. Fifteen citations (43 percent) directed governments to adopt measures for people living with or otherwise affected by HIV/AIDS. Most of these urged governments to take measures to address HIV/AIDS-related discrimination, and the majority of these citations emerged from CEDAW. The remaining five citations (14 percent) dealt with other specific measures to be taken by governments. It is interesting to note that among these directive citations, there was an almost equal balance between those related to prevention and those related to addressing the consequences of HIV/AIDS.

The following is an example of how a typical directive citation is worded. CEDAW delivered the following recommendation to the government of Zimbabwe in January 1998:

> The Committee urges the Government to increase its efforts to combat the HIV/AIDS pandemic, and to ensure that appropriate sexual and reproductive health information, education and services are provided to all women, and, in particular, to adolescents.[1]

Most directive recommendations addressing HIV/AIDS-related discrimination, like the one above addressing prevention and education, lack specificity. Occasionally, however, a monitoring body will refer to very specific information in order to direct a government to address a rights violation. For example, in its Concluding Observations to the government of Libya in May 1997, the CESCR recommended that

> foreign workers who are employed in the State party with valid work permits should not be deported if they become HIV-positive while in the country. It further recommends that the State party not treat the HIV/AIDS problem as one essentially related to foreigners, and that it take energetic steps by way of a publicity campaign in the media to inform its population of the nature of the disease, its modes of transmission, and what steps can be taken to avoid contracting it.[2]

The analysis showed that the majority of the Concluding Observations that contained references to specific cases or data emerged from the CESCR.

Some of the other recommendations addressed in directive citations called for governments:

- to address sex tourism in light of the epidemic;
- to promote the involvement of women political leaders in HIV information and education campaigns; and
- to gather specific data on the epidemic.

Gender Analysis of Concluding Observations and Recommendations

While CEDAW issued the highest number of gender-specific citations, which is not surprising given its mandate, those citations were generally focused on governments' obligation to ensure that women receive information, education, and appropriate services to reduce their risk of infection. That is to say, there were no comments that prodded or directed governments to ensure that their entire range of HIV/AIDS activities were gender-sensitive, or to ensure that gender-related economic, social, and political barriers to effective prevention were removed. Only one of CEDAW's nine directive recommendations focused on the protection of the rights of women with HIV/AIDS.

While the CESCR's Concluding Observations were generally more specific and targeted – using data to support their comments, questions, and recommendations – they rarely focused on the gender-related aspects of vulnerability to HIV or its disproportionate economic and social impact on women.

> While international human rights treaty-monitoring bodies have begun to address HIV/AIDS in the context of their work, much more is needed if human rights standards and mechanisms are to be effectively used to hold governments accountable for providing effective HIV prevention, care, and treatment programs and policies, especially for women and adolescent girls.

CEDAW's directive recommendations covered the broadest range of concerns in both prevention and care. Specific recommendations regarding girl-children and adolescent girls were limited to providing them with information, education, and services. While these recommendations are wholly supportive of our communities' advocacy to provide adolescents, especially girls, with information on sexual and reproductive health, we should also recognize that CEDAW failed to address HIV/AIDS-related discrimination directed at girls.

Finally, the HRC has failed entirely to address HIV/AIDS-related discrimination. I found this surprising, given that violations of the civil and political rights of people – especially women – living with or otherwise affected by HIV/AIDS have been the most visible rights violations throughout the history of the pandemic. Given the more highly developed jurisprudence of the HRC and the quality of information available to it through the work of mainstream human rights organizations that focus on civil and political rights, the fact that HIV/AIDS has remained absent from the HRC's Concluding Observations is also a reflection of how little attention those mainstream organizations have given to this pandemic. There is clearly a need for greater efforts to educate this particular treaty-monitoring body on the HIV/AIDS and other health dimensions inherent in its mandate.

Conclusions

As for the future, what this analysis shows us is that while international human rights treaty-monitoring bodies have begun to address HIV/AIDS in the context of their work, much more is needed if human rights standards and mechanisms are to be effectively used to hold governments accountable for providing effective HIV prevention, care, and treatment programs and policies, especially for women and adolescent girls. If we – as NGOs, AIDS service organizations, networks of people with HIV/AIDS, and activists – want to see the treaty-monitoring bodies challenge governments to meet their human rights obligations in HIV/AIDS policies and programs in a more sophisticated manner, then we have to recognize the role we have in educating the UN human rights machinery. In order to get to that point, the language of human rights needs to be central to our vocabulary of analysis and action. We who work in HIV/AIDS are in a position to add to the modern discourse and practice of human rights something that others have often ignored: the critical importance of the protection and promotion of economic and social rights.

Given the ever-growing body of information and analysis that we can provide, framed in human rights terms, UNAIDS and its co-sponsoring agencies have a significant role to play as a conduit for bringing that information to the attention of governments and the UN human rights machinery. Continued efforts to promote the implementation of the International Guidelines on HIV/AIDS and Human Rights[3] are critical.

With respect to women, the good news here is that we already have one human rights treaty devoted to protecting and promoting their human rights as women. But we need to ensure that the rest of the human rights machinery is made aware of the gender dimensions of HIV/AIDS that fall squarely within their mandates.

With respect to the rest of us, we need to be constantly vigilant in highlighting the gender-related dimensions of vulnerability to HIV/AIDS, and we need to allow that knowledge to guide our human rights approaches, whatever they may be, as we continue our efforts to bring this pandemic to an end.

– presented by Daniel Whelan

When this paper was presented to the Conference, Daniel Whelan was with the International Center for Research on Women. He is now in the PhD program at the Graduate School of International Studies, University of Denver, Colorado, USA. The research used in this presentation was further elaborated and expanded in November 1998. Please contact Daniel directly if you wish to receive information about the subsequent comparative analysis of these data. He can be reached at <dwhelan@du.edu>.

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[1] Committee on the Elimination of Discrimination Against Women. United Nations. UN Doc. /C/1998/I/L.1/Add.4, para 41, 28 January 1998.

[2] Committee on Economic, Social and Cultural Rights. United Nations. UN Doc. E/C.12/Add.15, para 24, 16 May 1997.

[3] Office of the United Nations High Commissioner for Human Rights (UNHCHR) and the Joint United Nations Programme on HIV/AIDS (UNAIDS). *HIV/AIDS and Human Rights: International Guidelines*. UN Doc. HR/PUB/98/1. Geneva, Switzerland: United Nations, 1998.

Training HIV-Positive People to Document Human Rights Violations in Asia

The Human Rights Initiative of the Asia Pacific Network of Persons Living with HIV/AIDS (APN+), presented at the Conference by Susan Paxton from Australia and Brett White from Hong Kong, is significant both in terms of deliverables and in terms of process. The deliverables include documentation of cases of human rights abuse in the Asia/Pacific region that will help identify problem areas and provide ammunition to challenge human rights violations. The process empowers the HIV-positive participants and increases their skills levels; it also increases awareness of human rights issues among people with HIV/AIDS and other community workers. This presentation explains that the Initiative grew out of a realization that a human rights response is central to the fight against AIDS. It then describes the objectives, major activities, and expected outcomes of the Initiative. Finally, it outlines activities planned for the future and expresses the hope that the Initiative may be adopted in other regions.

The APN+ Human Rights Initiative is an exciting and innovative project because it is the first systematic documentation of human rights violations of people with HIV/AIDS, and because the project is designed and implemented by people with HIV/AIDS. The Initiative is currently being carried out in eight countries by APN+. Funding has been provided by the Joint United Nations Programme on HIV/AIDS (UNAIDS).

Background

APN+ realizes that a human rights response has to be the cornerstone of the fight against AIDS. Almost universally, our first messages about AIDS are based on fear. This fear subsequently leads to a great deal of discrimination against people diagnosed as HIV-positive. Because of the discrimination faced by people with HIV/AIDS, people are reluctant to come forward to be tested. People will not come forward if they face being killed on the streets, as has happened in India. They will not come forward if they are going to be forcibly sterilized, as has happened in Thailand and other countries. They will not come forward if they are going to be denied access to treatment and care, or the right to employment, as has happened throughout the world.

Unless we challenge human rights violations of HIV-positive people, all prevention efforts will be thwarted. People will always look at HIV-positive people as “them” or “the other,” rather than relate HIV to themselves and take responsibility for protecting themselves from infection. However, before we challenge current practices of discrimination and begin to advocate for protection of the rights of HIV-positive people, we have to know where we are now in terms of human rights abuses. There is a great deal of anecdotal evidence that gross violations of human rights are happening to people throughout the world because of their HIV status. However, in most instances documentation of these human rights violations is lacking.

Objectives

The objectives of the APN+ Human Rights Initiative are to:

- develop a comprehensive understanding of the interrelationship between human rights and HIV/AIDS in the Asia/Pacific region;
- increase awareness of the specific nature and patterns of discrimination experienced by people with HIV/AIDS;
- build the capacity of people affected by HIV to respond to human rights abuses; and
- identify ways of working more effectively on human rights concerns with NGOs in the Asia/Pacific region.

Involvement of People with HIV/AIDS

In the past, human rights violations have been documented by experienced professionals. In this project, the documentation will be carried out by those most affected by the abuse – people who are themselves living with HIV. The people with HIV/AIDS are being trained on how to document human rights violations. This training is essential to the success of the project.

APN+ believes that there are some very good reasons for involving HIV-positive people in the data-collection process, including the following:

- HIV-positive people are best placed to monitor and report on violations of their rights.
- Because people with HIV/AIDS often live in fear of having their confidentiality breached, having HIV-positive people as the interviewers engenders an immediate

level of trust.
- Involving HIV-positive people builds an awareness of human rights among people with HIV/AIDS and provides them with the information to enable self-advocacy.

How the Initiative Is Being Carried Out

The Initiative involves six distinct activities:

1. Collate information developed by agencies and NGOs in the region concerning human rights and people with HIV/AIDS. APN+ first collected the relevant information and then developed an information pack that was given to HIV-positive people at the Human Rights Training Workshops (see below).
2. Conduct a generic workshop on HIV/AIDS and human rights for people with HIV/AIDS in the region. In November 1997, APN+ conducted a generic Human Rights Training Workshop in Thailand. The workshop was attended by over 30 delegates from 14 countries. Participants developed an overview of human rights issues, identified key concerns in the region, and affirmed their commitment to the APN+ Initiative.
3. Train people with HIV/AIDS in the documentation of the human rights of people with HIV/AIDS. HIV-positive people were recruited to take part in a five-day documentation training session held in Hong Kong in May 1998. Three criteria were established for selecting countries to take part in the training session: having known incidents of human rights violations; having HIV-positive people available with the capacity to undertake the documentation; and having the institutional support to carry out the project. UNAIDS provided funding for developing-country participants. Eight people attended from five countries: India, Indonesia, Philippines, Thailand, and Sri Lanka. Participants reported on the current human rights situation and AIDS policies in their respective countries. They developed a work plan for in-country data collection, including recruitment of interviewees and preparation of a resource list of sympathetic organizations that might support the Initiative.

   APN+ encouraged other countries to carry out simultaneous, parallel documentation. Representatives from Singapore, Hong Kong, and Australia made commitments to do so and also attended the training session in Hong Kong. UNAIDS has since agreed to support the Initiative in marginalized groups within developed countries; in particular, UNAIDS will support the documentation process among indigenous Australians.
4. Develop a data-collection instrument for human rights documentation. A significant focus of the documentation training session was the development and testing of a documentation tool for data collection. The tool that was developed is a standardized questionnaire/interview schedule based on the APCASO CompacT for Human Rights.[1] It encompasses all the types of discrimination people with HIV/AIDS may face, ranging from mandatory testing and breaches of confidentiality to compulsory segregation and loss of custody of children. The schedule lists eight areas (or domains) of discrimination: right to health; right to privacy; liberty, security and freedom of movement; freedom from inhuman and degrading treatment; right to employment; right to marriage and family life; right to education; and self-determination of affected groups.
5. Document human rights abuses in selected countries. The interviewers will conduct the first interviews of HIV-positive people in their countries, using the questionnaire/interview schedule. They will each speak to approximately 20 HIV-positive people and document their stories of discrimination.
6. Compile a report on human rights violations and HIV/AIDS and feed the information back to relevant agencies and organizations of people with HIV/AIDS in order to inform advocacy strategies. A report will be compiled at the end of this pilot project that will examine the impact of AIDS-related discrimination on the quality of life of people with HIV/AIDS. It will describe the critical human rights issues facing people with HIV/AIDS and attempt to identify mechanisms to address the documented concerns at both country and regional levels. The report will be fed back to local NGOs and organizations of people with HIV/AIDS. It will be used as an advocacy tool, a trigger to challenge and change attitudes and to move issues forward within each country. For example, it may be used to lobby hospitals to look at their policies on treatment and care of HIV-positive patients, or to lobby governments for legal reform.

Expected Outcomes

The expected outcomes of the Initiative are:

- increased capacity of HIV-positive people to address human rights violations;
- mechanisms to feed back findings in order to influence policymakers;
- advocacy strategies and policy guidelines for community action on

Continued from previous page.

human rights and HIV/AIDS; and
- stronger networks of NGOs and human rights groups in the Asia/Pacific region and mechanisms to maintain and monitor the input of people with HIV into these networks and groups.

Future Activities

We believe the APN+ Human Rights Initiative has the potential to move human rights forward not only in the Asia/Pacific region but also in other regions. In 1999 we plan to commence more extensive documentation (in India and Thailand, for example, we will recruit over 200 interviewees); develop a Human Rights Peer Documentation Training Package; and develop strategic interventions within specific countries.

As we scale up the project, and as the number of HIV-positive people trained in data collection increases, the awareness of the links between human rights violations and prevention will become stronger. This process should become self-sustaining and should lead to increased involvement of people with HIV/AIDS in policy development and decision-making; a stronger, more comprehensive regional human rights response to AIDS; and adoption of the Human Rights Initiative in other regions.

– *presented by Susan Paxton & Brett White*

Susan Paxton is the Australian representative on APN+ and the Human Rights Convenor for that organization. She is based at the Key Centre for Women's Health, University of Melbourne. Brett White is the Hong Kong representative on APN+ and the Human Rights Coordinator for that organization. He is based at AIDS Concern in Hong Kong. For more information, Susan can be reached at <s.paxton@pgrad.unimelb.edu.au> and Brett can be reached at <bwhite@es.hkis.edu.hk>.

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[1] The APCASO CompacT for Human Rights is a manual outlining the major areas of discrimination faced by HIV-positive people. Copies are available from the APCASO Regional Secretariat in the Philippines (see contact information elsewhere in this *Newsletter*).

Access to Treatment: AIDS-Affected Population in Costa Rica Wins Constitutional Challenge

A lawsuit in Costa Rica launched in 1997 by four people with HIV, described at the Conference by Antonio Matamoros, was successful in establishing the right of people with HIV to receive antiretroviral medications free of charge. This presentation traces the background of the lawsuit and describes the judgment of the Constitutional Court of the Supreme Court of Justice of Costa Rica. It also summarizes some lessons learned from the constitutional challenge.

As a result of a lawsuit brought by several people with HIV, the Supreme Court of Costa Rica has ruled that the government's National Health Care System must provide antiretroviral medications to the plaintiffs under the state's Social Security System.

> There is no army, which means that a greater percentage of the national budget can be spent on education and health programs, compared to some other countries in the region.

Background

Costa Rica is a Central American country with a population of about 3.5 million people. There is no army, which means that a greater percentage of the national budget can be spent on education and health programs compared with some other countries in the region. Health care is universal – every citizen has the right to health care and all its benefits. Officially, there are about 5600 known cases of HIV infection in Costa Rica, but the true number is believed to be much higher. One official with the Ministry of Health has estimated that by the year 2005 there will be approximately 34,000 cases of HIV infection in Costa Rica.

In 1992, several people with HIV/AIDS filed a lawsuit in the Constitutional Court of the Supreme Court of Justice, claiming that zidovudine (AZT) should be covered by Social Security. The Constitutional Court has a mandate to review compliance with the Constitution of Costa Rica. Its verdicts are of a declaratory nature; they are unappealable and enter into force immediately. The Court rejected this lawsuit, saying that in its judgment the medicine "cannot be translated into a cure, only into a certain and prolonged course of deterioration."

In 1996, after hearing of the improvements made possible by new antiretroviral medications, many people with HIV/AIDS began taking the new medications. However, because they were unable to pay for them, they made representations to the officials of the National Health Care

"Without the right to life, all the remaining rights would be useless."

System to get the System to provide the medications free of charge under Social Security. The Directors did not respond to these representations, nor did they show any disposition to dialogue. This process dragged on for two years and even though a government ombudsman organization – La Defensoria de los Habitantes – got involved, the health-care officials never showed any interest in paying for the medications.

In May 1997, in a separate case, the Constitutional Court ruled in favour of a group of people with HIV/AIDS who claimed they had been discriminated against in terms of the care they had received as patients in some hospitals.

Initially, people with HIV/AIDS were not very enthusiastic about the idea of a new lawsuit to get the National Health Care System to pay for the medications because the 1992 lawsuit had failed. However, as the new medications continued to prove to be effective for many people, as people continued dying because they could not afford these medications, and because of the encouraging precedent established by the May 1997 decision of the Court in favour of people with HIV/AIDS, some of the survivors decided to file a new lawsuit in the Constitutional Court.

The 1997 Lawsuit

The new lawsuit was launched in 1997 by four people with HIV, with the pro bono help of the same lawyer who filed the first lawsuit. He based his arguments on scientific and clinical evidence of the effectiveness of the new medications.

This time the Court ruled in favour of the plaintiffs and ordered the National Health Care System to provide the medications free of charge. The Court found that: (1) it has been demonstrated that the combination of the antiretroviral medications is able to prolong life even if it does not cure; and (2) the refusal of the National Health Care System to provide the medications free of charge is an illegal violation of the right to life of the plaintiffs, and is therefore unjustified.

The judges based their decision on the right to life and health as enshrined in the Constitution of Costa Rica, and as endorsed by Costa Rica in international treaties such as the Universal Declaration of Human Rights, the American Convention on Human Rights, the American Declaration of the Rights and Duties of Man, and the International Covenant on Civil and Political Rights.

The judges also cited the mission and functioning of the Social Security System as a fundamental pillar of a democratic system. They referred to the government's uncanceled debts in the Social Security System – ie, the government's own unpaid premiums to the National Health Care System – and that System's unwillingness to finance these medications. The Court said that

> if the right to life is especially protected in each modern state and, with it, the right to health, any economic criteria [sic] that pretends to deny the exercise (practice) of those rights, has to be of secondary importance because ... without the right to life, all the remaining rights would be useless. ... Of what use are all the other rights and guarantees, the institutions and its programs, the advantages and benefits of our social welfare system, if even one person is not able to count on, and be assured of, the right of life and health?

Aftermath

Shortly after the judgment was rendered, one of the plaintiffs died. Nevertheless, the other plaintiffs and families filed a lawsuit against the National Health Care System in order to be given the antiretroviral medications. The National Health Care System agreed to provide the medications to those people willing to undergo routine examinations (such as CD4 and viral load counts and other physical exams forming part of a standard medical protocol).

Lessons Learned

Four important lessons emerge from this experience:

- It is important for doctors specializing in HIV/AIDS, together with people with HIV/AIDS, to develop common knowledge about advances in treatment.
- At the outset, attempts should be made to promote a dialogue between people with HIV/AIDS, treating doctors, and health institutions.
- Advocates should be prepared to use the legal system of the state, basing the complaint on fundamental human rights.
- It is important to form organizations of people with HIV/AIDS fighting for their rights.

– presented by Antonio Matamoros

Antonio Matamoros is a person with HIV/AIDS and an agronomic engineer with an M.Sc. in Rural Sociology. He is a professor at the National University of Heredia and the National Open University, both in Costa Rica. Antonio was one of the plaintiffs in the lawsuit that is the subject of this presentation. For more information about this constitutional challenge, Antonio can be reached at <amatamor@samara.una.ac.cr>.

Proposed Use of the Criminal Law to Deal with HIV Transmission in Zimbabwe

A proposal to use the criminal law in Zimbabwe to prevent the transmission of HIV, described at the conference by Sheillah Kanyangarara, raises some serious concerns about whether such measures are appropriate and effective. This presentation outlines the conditions in Zimbabwe that led to the introduction of a bill to amend the common and criminal law. It lists the concerns that were raised about the bill and describes how opposition to the bill from community groups and others led to its being withheld. In conclusion, the presentation discusses a possible alternate approach to dealing with HIV transmission that encompasses African values.

The government of Zimbabwe drafted a bill in 1996 that would, among other things, make it a criminal offence to deliberately transmit HIV to an uninfected person. The bill has met with considerable resistance and has not been enacted in the time since it was presented to Parliament (a period of over two years).

Background

Zimbabwe has a population of 12 million people according to the last census update in 1992. It is estimated that 1.6 million people are infected with HIV. One in three women who access antenatal care is HIV-positive and there are two hundred AIDS-related deaths every day. Only a small proportion of the population has been tested for HIV. There is still widespread misinformation and misunderstanding about HIV and how it is transmitted.

For policymakers in Zimbabwe, the situation with respect to HIV can be compared to a juggling game: trying to control the epidemic in such a way that the uninfected do not get infected, the infected are not discriminated against, and everyone accepts that prevention of HIV transmission is their responsibility. It would be an understatement to say that any country faced with the same situation would have a difficult task, in light of the diverse interests that have to be balanced.

Rape in Zimbabwe

Currently, Zimbabwe is faced with a frightening increase in reported cases of rape, especially cases involving children under 12 years of age. In one of the three major rape trial jurisdictions, at least a hundred new cases of rape are scheduled for trial each week. Not a day passes without a report of rape in the country's main newspaper. As a result, there have been calls to increase prison sentences for convicted rapists from 10 years (the current sentence for a single count of rape) to 15 or 20 years. Some people have even called for castration or life imprisonment of rapists. Given this situation, Parliament is under pressure to deal with the question of rape in a decisive manner.

Customary marriage laws

In Zimbabwe, most marriages are not registered. They are contracted according to customary law, where *roora* is paid to the woman's family. Currently, the marriages are only recognized for purposes of maintenance, inheritance and, in some cases, insurance. Customary marriages are not recognized under criminal law. As a result, a man who pays *roora* for one woman and then goes to register marriage with another woman does not commit bigamy.

> If they do not disclose, they may be convicted by the courts; if they do disclose, they may be shunned by society.

Women's organizations in Zimbabwe are actively involved in lobbying politicians for changes to the law on customary marriages. Parliament has to a large extent been merely echoing the voices of the party and rubber-stamping actions of the executive. Nevertheless, women's organizations have boldly approached members of Parliament, individually and collectively, to advocate for changes to laws that affect women. As a result, the laws affecting women have been amended more than any other laws in the country.

Proposed Criminal Law Amendment

In 1996 a bill was drafted to amend the common and criminal law of Zimbabwe as follows: [1]

- to make deliberate transmission of HIV by infected persons to uninfected persons a criminal offence;
- to impose a mandatory prison term of up to 20 years on a person convicted of a sexual offence if it is proved that at the time of committing the offence, the person was

infected with HIV;

- to empower magistrates to order HIV testing for persons accused of sexual offences on their first appearance in court;
- to abolish the irrefutable presumption in Zimbabwean common law at the time that a boy under 14 years of age cannot have sexual intercourse; and
- to extend the circumstances in which customary law marriages are recognized.

In order for a person to be convicted of deliberate transmission of HIV, the person:

- must have actual knowledge that they are HIV-positive;
- must intentionally perform an act that transmits HIV or that is likely to lead to HIV infection; and
- must know that their act will or is likely to result in the infection of another person.

A person accused of deliberate transmission of HIV could use as a defence that fact that they disclosed their HIV status to the complainant.

No rationale was provided for the recognition of customary law marriages under criminal law. Gender activists concluded that the rationale for this recognition was to provide a defence for married men who transmitted HIV to their customary law wives.

Although the amendments do not specifically refer to “rape,” the provisions on mandatory prison sentences and HIV testing, and the provision abolishing the assumption that a boy under 14 years of age cannot have sex, all relate to rape. For example, the provision on mandatory prison terms could be used to impose a harsher sentence on a person convicted of rape if the person was HIV-positive (even if the person was unaware of their status). In addition, the power to order HIV testing of persons accused of sexual offences could be used against suspected rapists.

Reaction and Response

The proposed bill has proved to be very controversial, not only because it proposed to use the criminal law to deal with HIV transmission, but also because it threatened to pit gender activists against AIDS activists.

With respect to the proposals to criminalize HIV transmission, a number of concerns were raised:

- Because of the extent of HIV infection, and the many ways in which HIV is transmitted, the bill could result in large numbers of people being charged. This would create a multiplicity of cases to be investigated by already overworked police and to be tried by already overloaded courts.
- Since most people are not well-informed about the modes of HIV transmission, the bill could result in thousands of frivolous complaints being lodged with police. This would trivialize a very serious issue.
- Since, under the terms of the bill, for the proposed law to be invoked a complainant does not have to be actually infected with HIV but merely exposed to infection, the bill may result in malicious prosecutions – ie, people could report a case simply to spite a person with HIV/AIDS.
- There is uncertainty about how the courts would decide whether the accused has “actual knowledge” they were HIV-positive.
- There is a danger that the bill would lead to calls for mandatory testing on the grounds that this is the only way people can be expected to know their status.
- People may decide not to be tested because they would realize that if they do not know their status they cannot be convicted under the proposed law. This means that fewer people would seek testing and fewer people would be aware of their HIV status.
- There could be cases where it will be difficult to determine whether the accused intended to engage in an act that transmits HIV or is likely to lead to HIV infection – for example, when the accused was drunk or in a drugged state.
- The proposed bill would put pressure on HIV-positive people to disclose their status prior to engaging in sexual intercourse, but there are no protections in the bill to deal with breaches of confidentiality once the disclosure is made. There is no provision for non-disclosure of the name of the accused during the trial. Even if the accused is exonerated, people will remember that they are HIV-positive. The bill therefore leaves HIV-positive people engaging in sexual intercourse in a difficult position: If they do not disclose, they may be convicted by the courts; if they do disclose, they may be shunned by society.
- There are no confidentiality protections for the complainant.
- People with HIV/AIDS already face enormous stigmatization. The proposed bill would add more punishment – a criminal record and the threat of a 15- or 20-year prison sentence. Imprisonment would not accomplish much and would be detrimental to the health of the convicted person. This bill would impose stiff prison sentences at a time when penal

reform is moving away from viewing imprisonment as the best form of punishment.

- Some concerns were raised about the provision in the proposed bill for the accused to raise, as a defence, the fact that they disclosed their HIV status to the complainant.

While everyone agrees that both parties to a sexual act should behave responsibly and take appropriate precautions, should the seropositive partner be relieved of all responsibility merely by disclosing their serostatus to the seronegative partner? It has been argued that a driver would not go unpunished if they ran over a pedestrian who was standing in the middle of the road, even though the pedestrian may have been behaving irresponsibly.

This defence assumes that people will know their HIV status, what HIV is and what the implications of HIV are for a person's health. These are not realistic assumptions, given the levels of literacy and awareness of HIV in Zimbabwe.

This defence assumes that there is equality in relationships where there is a risk of HIV transmission. This is not an accurate assumption. Research that was conducted by the Musasa Project in Midlands in 1996 established that one in four women from the sample of the survey is forced to have sexual intercourse with a marriage partner.[2]

Conflicting Interests?

Given the vigilance of women's organizations in lobbying for recognition and protection of the rights of women, the decision to include, in the same bill, the criminalization of HIV transmission and measures to deal harshly with rapists had the potential to create discord among women's organizations and AIDS organizations.

Fortunately, this did not happen. Organizations dealing with both women's issues and AIDS issues (such as the Women and AIDS Support Network) realized that the interests of people with HIV/AIDS and the interests of women in general did not necessarily clash. Therefore, these groups invited other organizations that deal with women's rights (such as Women in Law and Development in Africa), organizations led by men that are at the forefront of women's issues (such as Padare), organizations dealing specifically with research into AIDS, and organizations that are seen as custodians of African customs (such as the Zimbabwe National Traditional Healers Association) to discuss the bill and to present a common front in responding to the bill.

Support was also sought from international organizations, which were asked to make specific comments on the bill. Their comments were sent to the Ministry of Justice, Legal and Parliamentary Affairs. Parliamentarians were invited to a lunch facilitated by the Working Group on Gender Politics, at which the bill was discussed clause by clause. The lunch was part of a series of monthly meetings held with women parliamentarians (in particular) to sensitize them to shortcomings in laws that affect women. To date, over two years after it was first drafted, the proposed bill has not seen the light of day. [3]

A Different Approach

Given the pitfalls of criminalization of HIV transmission as a means of preventing transmission, it is necessary to look at other possible solutions. The United Nations Joint Programme on AIDS (UNAIDS) recognizes that reducing the transmission of HIV requires a response based on the principles of public health care and not criminal law.

Although Western culture has had a very significant influence on African customs and beliefs, some of these customs and beliefs remain unchanged. The approach of my people, the Zezuru, and other peoples, to dealing with life-threatening illness may provide us with some guidance on how to deal with this issue. Within the Zezuru customs and tradition, we sympathize with anyone who has been affected by illness or tragedy. Death and illness are not private matters, but rather problems of the entire community. The whole community will openly grieve if anyone dies. Our approach to dealing with complications or misunderstandings is conciliatory and not confrontational. When someone dies in a family, a spirit medium is approached to establish why that person died. The emphasis is on why and not how. In other words, the fact that a person died because of complications of AIDS is irrelevant when compared to the question of why the person was stricken with AIDS in the first place. Furthermore, the family would want to know how it could have been avoided. After being told the reason why a person died, the family sits together to find a solution that will ensure that other people do not get affected by the same illness or tragedy. The overriding principle is the survival of the family and not punishment of the offender (if there is one).

This approach could very well be applied to dealing with the question of HIV transmission. Instead of wasting time pointing fingers in

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Instead of wasting time pointing fingers in court and placing blame, policymakers should sit together with the affected persons and find a conciliatory solution to the problem.

court and placing blame, policymakers should sit together with the affected persons and find a conciliatory solution to the problem. We need to deal with our attitudes before we can search our minds for a solution. In the words of Amos Wako, the Attorney General of Kenya:

> A hard judgemental and unreceptive attitude is certainly not the way to deal with the problem. Instead we should emphasise a more caring attitude.[4]

In the face of HIV/AIDS, there is no time to apportion blame, only time to find solutions.

– presented by Sheillah Kanyangarara

Sheillah Kanyangarara works as a freelance consultant in the area of human rights of women and AIDS. She is currently developing best practice guidelines on the treatment of survivors of sexual violence in light of HIV/AIDS with the AIDS Law Project, Wits University, Johannesburg. Sheillah can be reached at <akanya@mweb.co.za>.

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[1] Criminal Law Amendment Bill 1996. Substantive criminal law of Zimbabwe is based on Roman Dutch common law, while the law of evidence in criminal law is largely based on English common law. As a result, most of Zimbabwe's criminal law is unwritten. However, the law on consensual sexual intercourse with a woman above 15 years of age is based on amendments to the common law made by the legislature. This law is referred to as the Criminal Law Amendment Act, chapter 9:05. The bill under consideration sought to amend this amendment to the common law position.

[2] C Watts. The Magnitude of Domestic Violence in Zimbabwe. 1996.

[3] A query on 16 February 1999 to Ms Bridgette Chivizhe, a Principal Law Officer assigned to work on the bill in the Ministry of Justice, Legal and Parliamentary Affairs, revealed that the bill is still under consideration by the Department of Policy.

[4] A Mutandwa. The Meeting Point. *The Herald*, 23 May 1996.

Priorities for Public Funds: Crisis in National Leadership?

The economic downturn that has hit Southeast Asian countries has worsened what was already a very serious HIV/AIDS pandemic in that part of the world. In this presentation to the Conference, Marina Mahathir, of the Malaysian AIDS Council, describes how the countries in the region have gone from boom times to financial crisis within the last decade. The presentation points out that the funds that were being invested in HIV/AIDS prevention and care during the good times, and which were inadequate even then, have been sharply reduced as a result of the current crisis. The presentation argues that these reductions are shortsighted and will result in a need for even greater expenditures in future. Finally, the presentation puts forward, from an NGO perspective, what some of the government priorities should be in responding to HIV/AIDS.

I come from a country that until recently had one of the fastest-growing economies in Asia, if not the world. The events of the last eleven months, however, have changed the economic scenario in the Southeast Asian region in ways we could not have imagined at this time last year. Once robust financially, many countries in my region are now facing a situation where millions of people are unemployed and barely able to scrape together enough to buy food and daily necessities. Our currencies have been devalued, some to about one-eighth what they were a year ago, putting us at the mercy of foreign creditors. In some countries, such as Indonesia, this has led to political instability and change that have yet to be seen to result in any improvements in the economic situation.

If we superimpose HIV/AIDS onto this scenario, the picture looks very gloomy indeed. Even before the Asian economic crisis, the biggest rise in the pandemic was being experienced in Asia. It has been estimated by UNAIDS that by the year 2000, approximately half of the 60-70 million adults who will be infected by HIV will come from South and Southeast Asia.[1] That estimate was made during the "good" times. The reasons for these high numbers are plentiful: ignorance and denial in some countries, political instability in others, and a relative lack of funds in still others. Many countries in Asia, during times when they could have afforded to have very good prevention programs, had trouble coming to grips with the HIV/AIDS pandemic. With the possible exception of Thailand, government responses have been slow and often inadequate, while NGO responses have been limited.

Funding Cuts

With the economic crisis, which at the moment seems to be expanding, responses to HIV/AIDS have been

By the year 2000, approximately half of the 60-70 million adults who will be infected by HIV will come from South and Southeast Asia.

cut even more. In some cases, responses seem to have disappeared from the agenda altogether. Cuts across the board in public spending have meant that even prevention programs (in addition to the more expensive treatment and care programs) have suffered. In Malaysia, for instance, government grants to NGOs have been cut from a high of RM 1.8 million (about US$720,000 at the old exchange rates) in 1995 to about RM 129,000 (about US$32,250 at the current rates) in 1998.

Even within government programs there have been stringent cuts and a rearranging of priorities. It must be remembered, however, that these cuts were being made in health budgets that were not impressive in the first place. AIDS budgets were even less so. In 1990, at the beginning of the economic boom years, only three developing countries reported spending more than one percent of their national health budgets on HIV/AIDS. Two of these countries are in Southeast Asia: Thailand (at five percent) and Malaysia (at two percent).[2] There is nothing to indicate that during the boom years public spending on HIV/AIDS increased beyond these percentages, though the actual amounts may have gone up.

What is worrying about these cuts is, first, the suddenness of them – catching many AIDS programs off-guard – and, second, the fact that they are occurring at a time when there are even more people potentially at risk. The large numbers of people becoming unemployed – more than 10 million (five percent of the population) in Indonesia alone[3] – are all potentially vulnerable to risky behaviours and infection. The numbers of refugees and economic migrants have increased; the fact that many of them have illegal-alien status in host countries makes them vulnerable to all health problems, including HIV/AIDS. Conversely, retrenchment of foreign workers has meant that they often return to home countries where conditions are worse.

Even those people who are still employed become vulnerable due to higher stress levels and the fact that there are fewer prevention programs to educate them about HIV/AIDS. Community-based organizations and other NGOs working in HIV/AIDS, heavily reliant on either government support or public donations, have been very hard hit. They now have to try to raise more funds in an environment where people are unable to be as generous as before.

It must also be understood that the formerly fast-developing countries of Southeast Asia did not receive much financial support from overseas donors. Most donors favoured lower-income countries that have large epidemics. The donors rightly perceived that the more well-off countries could take care of their own. This situation has changed. The pool of poorer countries with NGOs needing help has increased, unfortunately at a time when many donor countries are also cutting their overall foreign aid budgets. The result of all this is a crisis for everyone working in HIV/AIDS in Southeast Asia.

Despite the old adage that prevention is better and cheaper than a cure, budgets for prevention are now limited, particularly for programs that work at the community level among marginalized groups and those most vulnerable to infection. In the good times, support for these programs was not consistent in all countries for many reasons (not just money). Particularly in Asia, many such programs had yet to show results. In assessments by UNAIDS Country Programme Advisers, prevention programs in most countries did not reach the majority of people most likely to contract and spread HIV.[4] According to the World Bank, while some prevention programs have attempted to encourage safer behaviour among those likely to contract and spread HIV, the coverage has generally been low.[5]

Program Cuts

If NGOs, with their limited capacities, struggled to deliver prevention and care programs in the past, they have even more difficulty delivering programs in the current crisis situation. Money is one problem, but so is the increase in numbers of people who may need their services. In some countries, because of particular political environments, NGOs already work under difficult circumstances. When these environments become unstable or even change altogether, adapting to these changes is not easy. Public sympathy toward marginalized groups and those stigmatized by their vulnerability to HIV or by being HIV-positive, diminishes in such environments.

On the care and treatment side, things are even more dire. All developing countries have faced problems in providing the level of treatment and care that is the norm in industrialized countries. While 90 percent of those who are HIV-positive live in the developing world, 92 percent of the estimated US$14.2 billion in expenditures on HIV/AIDS is spent in the industrialized world.[6] This means that most people who become infected with HIV in the developing world can only expect to have the barest minimum of care, if they receive any care at all. Most of these people will not have the benefit of the prolonged life expectancy that their counterparts in the developed world have thanks to their ability to access antiretroviral drugs. Even drugs to treat opportunistic diseases are not easily come by in many developing countries, bearing in mind that these countries have also had problems providing the most basic health care to their populations.

For the formerly relatively well-off countries of Southeast Asia, the provision of care and treatment for people with HIV/AIDS has always been a problem. Most of them come from low-income groups who seek free treatment in government hospitals. While many drugs are available to these patients, others, including antiretrovirals, have to be paid for because there is no national health insurance plan. The costs of these drugs have always been beyond the means of most people with HIV/AIDS and are even more so now. Even those who were able to buy them before are now often forced to stop treatment. The call to lower the prices of drugs means nothing when currencies have also been devalued; in some cases, despite the lowering of prices, the actual costs in developing countries have increased.

Furthermore, in some countries such as my own, there is an increasing trend toward the privatization of health care, where lower-income groups become even more disadvantaged. Even though private hospitals in many countries have been asked to designate 10 percent of their beds for the poor, as is the case in Malaysia, these beds are for all diseases, not just for AIDS. Therefore, the situation may arise where most people with HIV/AIDS will simply have nowhere to go.

It is important to remember that access to treatment is currently being denied to most people not only because of cost. Lack of knowledge and fear of stigma and discrimination prevent many people from seeking treatment. Little has been done to alleviate these two barriers to treatment, and there is no indication that they will be a priority in financially difficult times.

Care and support services provided by NGOs are also threatened. As the need expands for hospices, counseling, legal and employment services, and support groups for people with HIV/AIDS, families and others, NGOs are unable to meet that need, thus further adding to the problems of people with HIV/AIDS.

The sad irony of the situation is that even when countries recover from the economic crisis in the future, as we pray they will, the impact of the crisis-boosted HIV/AIDS pandemic will act as a barrier to full economic recovery. As prevention programs are cut now, more people will become infected who will require expensive care and treatment in the future. Where and how can they expect to get this care in the coming years? Since the financial burden of care is already enormous, how much greater will this burden be in the future? How do we predict the future social costs of AIDS, the numbers of orphans and other survivors to care for, and the extent of the depletion of the human resources required to rebuild these countries?

Need for Leadership

What is needed now to avoid this bleak future is for the leadership in all national AIDS programs to take another look at the priorities in terms of cost-effectiveness. The long-term view is essential; the temptation to do programs that supposedly provide immediate results needs to be avoided. There is a greater need to understand the epidemic within a country and how the economic crisis is impacting on it.

I would like to suggest what some of the priorities should be, from an NGO perspective:

- Prioritizing prevention programs among those who need it most, especially injection drug users, sex workers, and other marginalized groups that are best served by NGOs. Budgets should be targeted toward mobilizing NGOs and increasing their capacity to deliver their programs, and away from expensive mass-media campaigns for the general population, especially those with obtuse messages.
- Prioritizing transborder cooperation between countries to deal with issues such as migrant workers, and finding ways of sharing costs.
- Prioritizing prevention, care, and support programs for women, in recognition of their crucial role in the AIDS epidemic. The complete role of women in society – social,

educational, and economic – must be recognized, rather than their more limited role as vectors of infection to their babies. Programs to prevent mother-to-child transmission – which are favoured by many countries because of the almost immediate gratification of preventing some babies from becoming infected – must undergo strict cost-benefit analyses, especially in low-to-medium-prevalence countries. The proportion of money placed in these programs as compared with other prevention programs must be made more equitable. The undeniable biological, emotional, and social bonds between mothers, including HIV-positive ones, and their babies must not be ignored in the interest of saving these babies.

- Prioritizing and increasing the involvement of people with HIV/AIDS in prevention programs. This has been shown to be more realistic and effective, especially among peer groups and youth.
- Understanding that there are long-term economic and social benefits to providing adequate and equitable care and treatment. As expensive as care and treatment is now, it will still be cheaper than the total economic cost in the future of neglecting care now. Some developing countries have been able to provide antiretroviral therapies to their citizens. How these countries do so must be studied and, if feasible, emulated.
- Understanding that prioritizing HIV/AIDS in public funding benefits the general health of society. AIDS leads to an increased prevalence of other diseases, most often tuberculosis. Prioritizing STD prevention will also help HIV prevention.

The challenge for us all is how to maintain focus on HIV/AIDS when many more issues of national importance have come up.

HIV/AIDS, if relegated to low priority now, stands to restrict any hoped-for full recovery from the current crisis.

Conclusion

The leaders in all organizations working in HIV/AIDS in Asia, whether governmental or non-governmental, are facing the issue of how to remain effective in a time of great economic and political difficulty. The challenge for us all is how to maintain focus on HIV/AIDS when many more issues of national importance have come up. It has to be understood, however, that other issues, with good management and hard work, will eventually subside and hopefully even disappear. But HIV/AIDS, if relegated to low priority now, stands to restrict any hoped-for full recovery from the current crisis. No matter how small the HIV/AIDS problem may seem now, any neglect from focusing on other priorities will cause it to grow.

The result of that neglect will be counted in terms of a future where people are unable to enjoy the fruits of their labour because they are ill; where families are further impoverished by the need to spend on hospitalization and treatment; where many more children face the prospect of becoming orphans, with all the accompanying social disadvantages that such a status brings; and where society has to suffer the social impact of a disease that, ironically, is easily and inexpensively preventable. In an address to this Conference, Mr Callisto Madavo of the World Bank said that governments must be bold to effectively manage the epidemic. I would say that in difficult economic times, everybody needs to be even bolder, to resist the easy excuse of lack of money, in order to reap the long-term benefits.

– presented by Marina Mahathir

Marina Mahathir is the President of the Malaysian AIDS Council, an umbrella body for 32 NGOs working in HIV/AIDS in Malaysia. She is also Vice-President of the AIDS Society of Asia and the Pacific (ASAP) and represents Asia-Pacific NGOs on the Programme Coordinating Board of UNAIDS. In 1999 she will chair the 5th International Congress on AIDS in Asia and the Pacific (ICAAP) in Kuala Lumpur, Malaysia. Marina can be reached at <netra@pop.jaring.my>.

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[1] UNAIDS/WHO Working Group on Global HIV/AIDS and STD Surveillance. *Report on the Global HIV/AIDS Epidemic*. December 1997.

[2] M Ainsworth, M Over. *Confronting AIDS: Public Priorities in a Global Epidemic*. World Bank Policy Research Report, 1997.

[3] Conservative estimates of more than 10 million unemployed in Indonesia. *Asiaweek*, 18 May 1998.

[4] Supra, note 2.

[5] Ibid.

[6] J Mann, D Tarantola (eds). *AIDS in the World II*. New York: Oxford University Press, 1996.

Human Rights: Consequences for the HIV Epidemic – Beyond Policy Consensus to Effective Activism

The lack of progress in responding to HIV/AIDS in South Africa and in many other countries in the South is largely due to the fact that these countries lack an effective and assertive activist community. This is the major thrust of the presentation to the Conference made by Mr Justice E Cameron of the High Court of South Africa. The presentation traces the links between health and human rights and between human rights abuses and vulnerability to HIV/AIDS, and praises the International Guidelines on HIV/AIDS and Human Rights as the most important international human rights policy response to the epidemic to date. The presentation discusses the differences in how the North and the South have responded to the epidemic. It then describes how South Africa has developed a sound and comprehensive National AIDS Plan, but has made little progress in implementing the plan despite the fact that it has the fastest growing epidemic in the world. The presentation concludes that the problems in bridging the gap between North and South are due not to lack of policy but rather to a failure to implement these policies.

From a panic that at first seemed to affect only white gay men in New York City and San Francisco, AIDS is now recognized as a world phenomenon that, in numbers, most drastically affects heterosexuals in Africa.

This Conference comes at the end of seventeen long years of the epidemic. From a panic that at first seemed to affect only white gay men in New York City and San Francisco, AIDS is now recognized as a world phenomenon that, in numbers, most drastically affects heterosexuals in Africa.

The settings in which the epidemic was first recognized, and those in which its effect is now felt most painfully, could not be more divergent. The epidemic was first noted in a mainly white minority community in the midst of the most affluent society the world has known. Its effects reign most terribly now in an overwhelmingly black, heterosexual community, on a continent characterized by extensive poverty and human displacement, and which enjoys the least economic growth in the world.

In their social situation, political priorities, and capacity for action, these two communities seem unbridgeably different from each other. But I want to question whether the gap is in fact as wide as it seems. And I want to argue that it is a condition of a successful and credible world response to the epidemic that it should be bridged. My argument proceeds by examining the lessons the experience of the one holds for the other.

Lessons and Insights

These past years have taught us some lessons that lie bitter in our mouths. These have concerned principally our limits as scientific and social beings. The lessons are as follows:

- We have become better acquainted with the limits of medical science (in 1984, the United States Secretary for Health and Human Services, Margaret Heckler, envisaged that the identification of the virus that causes AIDS would lead to a vaccine and a cure by 1990:[1] in 1999, we are still far from both) and with the shortcomings of medical treatment.
- The epidemic has exposed us to the most censorious, fearful, and prejudiced elements of our own societies. In South Africa, as recently as February 1997 the admission of an eight-year-old boy with AIDS, Nkosi Johnson, to a public school in a predominantly white suburban area, caused a crisis reminiscent of those in the US in the mid 1980s.[2]
- The epidemic has shown us the grievous shortcomings of governments in taking effective, wise, and humane action in the midst of the epidemic. Justice Michael Kirby of Australia censured them at the Fourth International Congress on AIDS in Asia and the Pacific as "unresponsive, centralised, out of touch governments."

These are painful and humbling insights. But the past seventeen years have also brought fresh and more hopeful insights about human responses in a health crisis. These have represented significant gains, and they embody important progress

From a human rights perspective, the most important gain the epidemic has brought is our greater insight into the connection between health and human rights.

in how we understand our own responses to AIDS.

From a human rights perspective, the most important gain the epidemic has brought is our greater insight into the connection between health and human rights. Here two closely related perceptions have added significantly to our understanding of our responses to a public health crisis:

- The first is that attempts to contain the epidemic effectively require respect for human rights. Justice Michael Kirby has called this "the HIV paradox":[3] the realization that sound reasons rooted not only in respect for human dignity, but in effective public health planning, necessitate a just and non-discriminatory response to AIDS; that recognition of and respect for individual human rights does not impede prevention and containment of HIV, but enhances it.
- The second gain, interrelated with the first, concerns the historical track of the epidemic. It derives from what Professor Jonathan Mann described as the "very intense, emotional, and personal" discovery,[4] in the course of the 1980s, of empirical and theoretical connections between human rights abuses and vulnerability to HIV/AIDS:[5] "How, 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."[6]

The importance of these insights is now widely accepted.[7] The recognition of these insights, especially the first one, constitutes the core of the most important international human rights policy response to HIV/AIDS the epidemic has yet produced.[8] These are the International Guidelines on HIV/AIDS and Human Rights.[9]

The Guidelines contain twelve policy directives. These reflect the drafters' recognition that protection of human rights is essential not only to safeguard human dignity in the context of HIV/AIDS, but to ensure an effective, rights-based response to the epidemic. Most fundamentally, the Guidelines embody the assertion that public health interests do not conflict with human rights (para 15 of the "Introduction" to the Guidelines).

The absolute gain that these insights represent can hardly be overestimated. Seventeen long years have seen enormous abuses experienced, where the insights have not been recognized. But the International Guidelines also raise an urgent question. How do we apply the benefit of the insights the past years have brought us to "bridge the gap" between North and South, between rich and poor in the epidemic? Here I believe that the lessons my own country, South Africa, holds may suggest an important further truth to be added to the insights already mentioned.

South Africa's Response to the Epidemic

Recognition of the importance of human rights was an article of faith in our national response to the epidemic in South Africa. In South Africa and elsewhere on the continent, there have occasionally been insulting suggestions that the human rights principles of confidentiality and consent and individual respect do not apply in Africa.[10] These suggestions still occur, and they are made not only, or even principally, by anti-African racists. Some emanate from Africans themselves, who seek to challenge the human rights premises of the continental response to the epidemic by belittling them as "alien" to Africa. But the principles have survived, and been endorsed and accepted, because they underlie the thinking of African people themselves about human dignity.

In South Africa, an effective national response to the epidemic began with the unbanning of the African National Congress (ANC) in 1990.[11] It culminated in the adoption by the ANC government in August 1994 of a National AIDS Plan that was the product of a nationally inclusive process of participation and consultation. The Plan reflected a sober and realistic but humane approach to the epidemic. It proposed a holistic and multisectoral response, including education and prevention, counselling, health care, and research. The Plan's emphasis on law reform and human rights principles "demonstrated an understanding of the relationship between human rights and public health."[12] It was envisaged that these principles would be implemented within a constitutional framework of rights protection that is among the finest and most detailed in the world.[13]

So, we have indeed a carefully crafted, soundly expressed, and comprehensive National Plan. It is based on policies and insights that conform with the most perceptive principles of disease management and public health containment recognized anywhere in the world. Yet, four years after democracy, the Plan still lacks almost any significant implementation. Our capacity for implementing it has proved to be severely limited, and AIDS has not appeared to feature strongly among major governmental priorities.[14]

Evidence from Thailand and Uganda suggests that personal involvement by respected leaders can make a perceptible difference to infection rates and in national responses to the epidemic. Yet our President, one of the twentieth century's moral titans, does not seem to many to have made any visible commitment to the epidemic. His most signal statement on AIDS was made outside the country, at the World Economic Forum in Davos, Switzerland, in February 1997.[15] Nothing inside the country has approached the profile or significance of President Mandela's Davos speech.

Instead of an urgent and overriding executive and governmental commitment to implementing the National Plan, there has been a tendency to succumb to the lure of "quick-fix" solutions. This has been visible in the allocation of a considerable sum of money, vast by South African standards, to what is now accepted as having been an ill-considered and misconceived educational intervention. This ended in the useless dispersal of the allocated funds. Also, it not only resulted in widespread ridicule of government's educational efforts, but contributed to corrosive public scepticism about the value of all AIDS interventions.[16]

The lure of misguided "quick-fix" solutions was also evidenced in the high executive access and endorsement accorded an untried, untested, and unauthenticated drug whose antiretroviral benefits are disputed and whose physiological consequences appear to be damagingly toxic.[17]

All this has taken place while the national rate of infection has resulted in South Africa now having the fastest-growing HIV epidemic in the world.[18]

Some countries may be battling AIDS issues more acute than South Africa's. It is certain that many countries have far less benign governmental approaches to AIDS than South Africa has. From a North American and Western European perspective, new drug therapies based on antiretroviral combinations have greatly reduced anxieties about the epidemic. Against this background, many of these observations about the South African national response to the epidemic may seem parochial. Yet I do not believe that they are. They demonstrate a further important insight that the past seventeen years have brought to us. They also provide the basis for considering further collective action in the epidemic.

Different Approaches

The insight stems from the striking paradox the case of South Africa demonstrates. When the epidemic started in North America and Western Europe, at least in the United Kingdom and the United States,[19] unsympathetic governments were in power who seemed to consider that the epidemic did not touch the concerns of their major constituents. Despite this, the battle for control of public health priorities and for the implementation of effective measures of control and care was won.

By contrast, South Africa started with a government publicly committed to justifiable policies, and with a National Plan that conformed in every respect with what was known to be wise and humane in responding to the epidemic. Yet we have shown almost no progress in implementing it. On the contrary, we have watched feared projections grow into a living nightmare around us, as infections among South Africans seem to be nearing one in five.[20]

There are undoubtedly many reasons for the existence of this paradox. Democracy has brought South Africans the benefits of self-respect, self-assertion, and self-government. Yet South Africans have become wiser and sadder as their experiment with constitutionalism has matured. The heady elation of the first years of the transition has given way, in both the public and the private sectors, to more sober realizations. We are a poor country with limited resources and limited human capacities. Governance is a complex and demanding task that requires extraordinary levels of public- and private-sector skill and commitment, neither of which have necessarily always been evident. Furthermore, translating plans and policies into practical reality is an arduous and exacting task.

The new and sober national mood is perhaps most painfully reflected in the battle against the AIDS epidemic. The part that lack of resources and skills has played in how the epidemic flood has washed up around us should not be underestimated. But it should also not be overestimated. South Africa's Department of Health has attained striking successes in other areas. These include curtailing cigarette advertising and heightening public awareness of the dangers of smoking; procuring the skills of Cuban doctors to work in underserved areas; and extending primary

> South Africa's problem has not been the lack of humane policies, well-founded in experience of the epidemic. It has been the lack of clear-sighted and principled activism to impel government to implement what it already knows is right.

health care to many who previously lacked it.

All of this contrasts painfully with our lack of resolve and immediate action in response to AIDS. For example, on 25 February 1997 the South Africa Law Commission submitted a report to the Minister of Justice detailing five urgent legal interventions the epidemic immediately required (condom standards; disposal of syringes; national regulations on communicability; the promulgation of a national policy on testing for HIV; and infection control measures in the workplace). This First Interim Report on HIV/AIDS was tabled in Parliament on 28 August 1997. On 18 September 1997, the National Assembly resolved that government should implement its recommendations urgently. Apparently in January 1998, the Department of Health decided to move on implementing "almost all" of the recommendations. On 23 February 1998, the Director-General of the Department wrote envisaging a meeting in which implementation would be discussed. The five recommendations, none of which were controversial and none of which require statutory amendments, have still not been implemented.

Further reasons must therefore be found to explain our frightening lack of success in the epidemic. The answer lies, I believe, in the most telling difference between our situation and that of the communities and countries where AIDS was first identified – ie, the fact that we lack an effective and assertive activist community.

Role of Activism

The response where the epidemic was first observed has demonstrated that a well-mobilized, aware, and determined community has the capacity to respond with vigour and insight to a health crisis that threatens its existence.[21] The triumph of the gay communities of North America and Western Europe has been profound. They fought injustice and bigotry; they changed public attitudes; and they reshaped governmental and private-sector priorities and programs. By doing so they not only protected themselves from some of the most extreme effects of the epidemic, but they also succeeded in enlarging their hard-won civic freedoms when they were most at risk.

South Africa's community of activists affected by HIV/AIDS is not yet beyond its fledgling stages. It has not yet gained the experience or acquired the organizational base from which to demand effective governmental action. South Africa's problem has not been the lack of humane policies, well-founded in experience of the epidemic. It has been the lack of clear-sighted and principled activism to impel government to implement what it already knows is right.

In seeking to "bridge the gap" between North and South, between rich and poor in the epidemic, the world's problem, also, does not seem to be with policy. The International Guidelines reflect a widespread consensus on policy of which those involved in HIV/AIDS can everywhere be proud. The world's problem, like that of South Africa, is with the implementation of these policies. What is most perceptibly lacking in most areas where the epidemic is uncontained is the angry demand of those most painfully affected by AIDS and HIV for effective governmental action.

> In the world from which I come, the epidemic cuts with all the sharpness and horror and dismay and often powerlessness of New York and San Francisco seventeen years ago.

The lesson and the warning from Africa is that the adoption of wise and sensible and sound policies is not enough; that goodwill and good intentions by themselves are insufficient; and that politically righteous commitments and insights by themselves do nothing to stop the raging fires of an epidemic that is reaching into the very core of our population.

This, no doubt, is an unsurprising conclusion. To many, it will seem obvious. But to those of us living in Africa, it is as critical as the recognition of human rights principles themselves. Most important, it suggests a call to immediate action.

Those parts of the world where the epidemic was first identified have the greatest access to the new drug therapies. In the world from which I come, for most rural poor people and for many in the cities there is no education, little or no effective health care, and no public housing. In that world, the epidemic does not cut with the blunted edge of post-therapeutic opportunity. It cuts with all the sharpness and horror and dismay and often powerlessness of New York and San Francisco seventeen years ago.

It was that horror and anguish that impelled the creation of one of the most effective activist movements of the twentieth century. The lessons and the impetus of that movement must not be spilled pointlessly on the warm sands of Northern Hemisphere affluence and contentment. The epidemic calls everyone concerned about it to a new consensus about the necessity of worldwide activism on AIDS.

The adoption of the International Guidelines on HIV/AIDS and Human Rights demonstrates what determined collective energy can produce. Those Guidelines are certainly an essential ingredient of successful further worldwide action in the epidemic. But on their own they will not be enough. For their implementation, they need to be partnered with anger. They need to be supported by a determination to see them implemented by governments in Asia, Latin America, and Africa that do not have the resources to supply the millions with HIV and AIDS whom they govern with effective drug therapy.

This Conference should therefore make a practical call to practical action from AIDS activists everywhere. The gap between rich and poor in this epidemic can be bridged by applying pressure to governments in the North and the South. This will lead to practical and beneficial effects, for example:

- Continuing pressure on drug companies by North American and European activists can help ensure that drugs – such as AZT for pregnant mothers to reduce vertical transmission during parturition – may be made available in affordable measure.
- Continued pressure on Northern Hemisphere governments to encourage an urgent perception of priorities in their counterparts elsewhere will translate speedily into productive local initiatives.
- Where action in such countries by senior government officials may imperil observance of human rights norms,[22] a firestorm of enraged resistance from throughout the world will assist local activists to counter the threat.

More than before, the world now needs the passion, the anger, the enthusiasm, and the support of the activist communities that shaped international responses to the epidemic in the 1980s.

The very drug therapies whose availability has seemed to reduce the urgency of the epidemic in the Northern Hemisphere were, in part, the product of activist anger and determination. Most imperative of all, that anger, and the resourcefulness and skill that channeled it effectively, must now be directed to the countries where effective governmental action against AIDS is most desperately needed.

More than before, the world now needs the passion, the anger, the enthusiasm, and the support of the activist communities that shaped international responses to the epidemic in the 1980s. As the epidemic has swelled to a flood tide in our countries, we call for a renewed pledge of effective activism from the worldwide community of those affected by HIV.

The pain and grief and hopelessness of the early years of the epidemic was translated through the moral stature and courage of those most touched by it into effective action against HIV/AIDS. That, the most important lesson of the past seventeen years, must now be brought to full realization when the world needs it most.

– presented by Mr Justice Edwin Cameron

Mr Justice Edwin Cameron, a former human rights lawyer and activist, co-drafted the Charter of Rights on AIDS and HIV and co-founded the South African AIDS Consortium and the AIDS Law Project. He is currently chair of the South African Law Commission's Project Committee on AIDS and HIV. Edwin can be reached at <160cam@atlas.wits.ac.za>.

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[1] R Bayer, DL Kirp. Conclusion. In: Kirp & Bayer (eds). *AIDS in the Industrialized Democracies: Passions, Politics and Policies*, 1992, at 377.

[2] See SA Law Commission Interim Report, Project 85: HIV/AIDS and Discrimination in Schools, para 2.13 note 38

[3] *National AIDS Bulletin* vol 10 no 4 at 6; *Canadian HIV/AIDS Policy and Law Newsletter* 1997; 3(2/3): 50-52.

[4] In: LO Gostin, Z Lazzarini. *Human Rights and Public Health in the AIDS Epidemic*. New York: Oxford University Press, 1997, at 167.

[5] JM Mann, D Tarantola (eds). *AIDS in the World II: Global Dimensions, Social Roots, and Responses*. New York: Oxford University Press, 1996, at 464.

[6] This insight, unlike the first, may not be universal, since in some African countries it is precisely the mobility and relative affluence of some members of society that has introduced them to HIV.

[7] This is not to brush aside the continuing debate about "AIDS exceptionalism." See R Bayer. Public Health Policy and the AIDS Epidemic: An End to AIDS Exceptionalism? *New England Journal of Medicine* 1991; 324 (23 May): 1500; S Burris. Public Health, AIDS Exceptionalism and the Law. *John Marshall Law Review* 1994; 27: 251; C Burr. The AIDS Exception: Privacy vs Public Health. *Atlantic Monthly* June 1997, at 1. But that debate is ancillary because Bayer's thoughtful challenge does not seem intended to suggest, and does not unavoidably entail, human rights curtailments. Its resolution need therefore not touch the premises of the "HIV paradox."

[8] For a short, useful overview of "AIDS discrimination" and human rights responses to it preceding the International Guidelines, see J O'Malley. Tolerance and Discrimination, at 466-467; and (unattributed). Human Rights Primer, at 467-468 of Mann & Tarantola, supra, note 5.

[9] The Guidelines are the product of the Second International Consultation on HIV/AIDS and Human Rights, Geneva, 23-25 September 1996, and were published by the United Nations, New York, in 1998. They were formulated and issued under the aegis of UNAIDS and the United Nations High Commission for Human Rights, and adopted by the Commission on 20 January 1997. For a summary of the Guidelines, see: Guidelines on HIV/AIDS and Human Rights Adopted. *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 1, 45-49.

[10] The suggestions stemmed from the erroneous assumption that the emphasis on community in African traditional law (as to which, see Alkas & Shandera. HIV and AIDS in Africa: African Policies in Response to AIDS in Relation to Various National Legal Traditions. *Journal of*

Geneva98: Abstracts on Legal, Ethical, and Human Rights Issues

There were over 80 abstracts at the Conference touching on legal, ethical, and human rights issues. The topics addressed in these abstracts ranged from the precarious human rights situation of men who have sex with men, and transvestite sex workers in Guatemala City, to the inadequacy of existing laws to prevent HIV/AIDS-related discrimination in Africa, and to the use of a human rights approach to reducing women's vulnerability to HIV/AIDS in all countries. A large number of abstracts dealt with access to treatment issues. Another popular topic was ethical issues in HIV/AIDS research. A number of abstracts focused on human rights education among a variety of target audiences, including people with HIV/AIDS, women, lawyers, and prevention and care support workers. There were also several abstracts on the rights of children and adolescents.

It was not possible to include all these abstracts in this special issue of the *Newsletter*. The following abstracts have been chosen because, when taken 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. Three of the abstracts deal with the use of the criminal law to deal with HIV transmission. Another three abstracts address issues around counseling and testing of pregnant women. Two abstracts touch on the use of laws to protect the rights of people with HIV/AIDS and to reduce stigma and discrimination. Another two abstracts discuss ethical issues in HIV research. Finally, there is one abstract on each of the following topics: HIV work being undertaken by lawyers, and the information needs of these lawyers; legal and ethical issues in providing care to injection drug users with HIV/AIDS; the determinants of HIV risk and vulnerability of children and how these relate to the rights of children; and spousal notification requirements.

Abstract 44105: State Efforts to Reduce Perinatal HIV Transmission

Background: For women with HIV/AIDS, zidovudine taken during pregnancy, birth, and by the baby after birth reduces the risk of perinatal HIV transmission from about 24 percent to 8 percent. The United States (US) Public Health Service (PHS) recommends that all pregnant women receive education, counseling, and testing (with consent) for HIV infection, followed by antiretroviral treatment for women with HIV/AIDS, and monitoring of newborns to provide early treatment for those infected. Policymakers need to assess state efforts to comply with PHS guidelines and other preventive measures.

Continued from previous page.

Legal Medicine 1996; 17: 527 at 531) entails gross disrespect for individual autonomy and dignity.

[11] See the historical overview by M Heywood, M Cornell. Human Rights and AIDS in South Africa: From Right Margin to Left Margin. In: *Health and Human Rights* vol 2 no 4, at 61-68.

[12] Ibid at 66.

[13] See my discussion in: Rights, Constitutionalism and the Rule of Law: The Alan Paton Memorial Address. *South African Law Journal* 1997; 114: 505.

[14] Heywood & Cornell, supra, note 11, set out the evidence powerfully. See also M Heywood. No brakes on AIDS holocaust. *Weekly Mail and Guardian* 15 May 1998.

[15] The address is reprinted in *AIDS Analysis Africa* 1997; 7(6): 1.

[16] The "Sarafina" debacle is partly documented in the Report in terms of section 8 of the Public Protector Act, 1994, as: Investigation of the Play Sarafina II. 1996.

[17] On the "Virodene" controversy, see the Johannesburg *Sunday Times* 8 March 1998.

[18] See South African national Department of Health. Summary results of the eighth national HIV survey of women attending ante-natal clinics of the public health services in South Africa in 1997. This states that "South Africa is considered to have one of the fastest growing HIV epidemics in the world." This statement was repeated by the Minister of Health, Dr Nkosazana Dlamini Zuma, in Parliament in March 1998. See *Weekly Mail and Guardian* 15 May 1998.

[19] R Shilts. *And the Band Played On: Politics, People, and the AIDS Epidemic*. St Martin's Press, 1987.

[20] Summary results, supra, note 18, show that an estimated 16 percent of the women attending antenatal clinics of the public health services nationally were infected with HIV at the end of 1997. This represents a 13 percent increase in the prevalence of HIV infection since 1996. HIV infection in KwaZulu/Natal province was estimated to be 26.9 percent.

[21] R Bayer. AIDS: Human Rights and Responsibilities. *Hospital Practice* 15 February 1994: 155 at 162: "I do not think that 15 years ago anyone would have anticipated that it would be possible for the gay community to organise itself so effectively as to persuade gay men to adopt radical modifications of their sexual behaviour."

[22] South Africa's senior health bureaucrat in December 1996 questioned the value and applicability in Africa of confidentiality and privacy norms: see Heywood & Cornell, supra, note 11 at 75.

Methods: We surveyed 50 states, the District of Columbia (DC) and the US territories to collect laws, regulations, policies, and programs intended to implement PHS guidelines through education, counseling, testing, and treatment of pregnant women and monitoring and treatment of newborns exposed to HIV.

Results: As of 2/98, 45 states/territories have responded. The majority of states have policies or guidelines to prevent perinatal HIV transmission. 87 percent have policies on counseling and/or testing of pregnant women, 77 percent on treatment of pregnant women, and 44 percent on testing, monitoring, or treatment of newborns. Only 36 percent of states have adopted laws or regulations on HIV counseling and testing of pregnant women: 28 percent require that HIV testing be voluntary; 2 percent routinely test women but permit them to "opt out"; and none mandate testing. Fewer states (22 percent) have laws or regulations regarding testing, monitoring, or treatment of exposed newborns. 13 percent expressly permit testing of newborns without parental consent. Most laws regarding disclosure of test results mirror state HIV confidentiality provisions. 55 percent of states criminalize intentional HIV transmission. 13 percent of states have proposed or pending legislation in one of the areas surveyed. Virtually all states have programs to disseminate educational information to health-care providers, pregnant women, and the public. States report ongoing assessments of practices of providers serving pregnant women (58 percent) and newborns (31 percent), as well as the impact of the PHS guidelines on rates of perinatal HIV transmission (33 percent). State assessment projects planned for practices related to pregnant women or newborns (26 percent) and perinatal transmission (28 percent).

Conclusions: States have moved rapidly to implement PHS guidelines. The majority of states have policies, fewer have formal legislation. Most efforts rely on education, counseling, and testing (with consent) of pregnant women. Treatment of pregnant women is mostly covered by policies. Fewer states have laws or policies regarding newborns. State efforts include little mandatory or coercive actions. Policymakers should consider ongoing evaluation data before changing existing state efforts.

Abstract presented by Zita Lazzarini,[1] LO Gostin,[2] JW Ward,[3] PL Fleming,[3] VS Neslund.[3]

[1] Harvard School of Public Health, 218 West Madison Ave, Holyoke, Boston, MA; [2] Georgetown University–Johns Hopkins School, Washington, DC; [3] Centers for Disease Control and Prevention, Atlanta, GA.

Abstract 473*/44101: Developing Policies on HIV/AIDS and Pregnancy that Respect Law, Ethics and Human Rights

Issue: For many years, legislators and policymakers have been debating how to offer HIV counseling and testing to pregnant women. Four main options have been considered: (1) HIV counseling and testing only in the presence of risk factors or on request; (2) routine HIV counseling and voluntary testing of all pregnant women; (3) routine testing of all pregnant women, with a possibility to opt out; and (4) mandatory HIV counseling and testing of all pregnant women. Recent and emerging results demonstrating the effectiveness of ante- and post-natal use of antiretrovirals and combination therapies to minimize the risk of perinatal HIV transmission has created significant pressure to ensure that all pregnant women are tested for HIV. There is a serious risk that the basic rights of pregnant women will be swept aside in the rush to respond to these innovative therapies.

Project: (1) The legal, ethical, and human rights issues raised by HIV testing of pregnant women, in Canada and internationally, have been researched and analyzed; (2) a short review of the issues has been included in a discussion paper on HIV testing and confidentiality; (3) an in-depth analysis of the issues has been undertaken in a paper on HIV and pregnancy; (4) comments on both papers have been solicited; (5) a final report has been published.

Results: An approach to testing of pregnant women is suggested that meets the challenge of ensuring that all HIV-positive women who desire to continue a pregnancy are offered effective means to reduce the risk of HIV transmission to their babies while respecting the rights of all pregnant women to decide for themselves whether to be tested for HIV. Policies should be developed to: (1) ensure that all pregnant women are offered the opportunity to undergo informed and voluntary HIV testing during pregnancy; (2) avoid coercive measures such as routine or mandatory testing of pregnant women, which involve an undue interference with the autonomy rights of pregnant women and cannot be justified as a matter of law or medical necessity.

Presented by Lori Stoltz,[1] L Shap,[2] R Jürgens.[2]

[1] Goodman and Carr, 2300-200 King St West, Toronto, Canada; [2] Canadian HIV/AIDS Legal Network, Montréal, Canada.

Abstract 44107: Mandatory HIV Testing of Pregnant Women: Will It Achieve a Reduction in Pediatric AIDS?

Issue: Policymakers are considering imposing mandatory HIV testing of pregnant women to increase the use of interventions to reduce the likelihood of perinatal transmission.

Project: Given the logistical requirements of the mothers' ongoing cooperation in undergoing treatment to reduce the likelihood of perinatal transmission, delays in transmitting positive results, and the disincentive to counsel with a mandatory testing program in place, using mandatory newborn HIV testing in New York State as an example, HIV Law Project Director will analyze effectiveness of this approach.

Results: Mandatory HIV testing of pregnant women will not ensure women's participation in treatment regimens to reduce perinatal transmission of HIV. It is not proven that mandatory HIV testing of pregnant women is the most effective approach for reducing perinatal transmission.

Presented by Theresa McGovern. HIV Law Project, 84 Broadway, Suite 608, New York, NY, USA

Abstract 44117: The Criminalization of HIV Transmission in the UK

Issue: Recent international convictions of people who have transmitted HIV to others have led to a debate about the introduction of legislation that would facilitate the prosecution of such people in the United Kingdom. The matter is of particular urgency now, since the UK government is currently reviewing the law on offences against the person and plans to introduce amended legislation in this area in the near future.

Project: As part of its continuing concern to monitor and comment on law that impacts upon those with HIV and AIDS, the Terrence Higgins Trust (THT) has undertaken a review of the efficacy of legislation that would facilitate the prosecution and conviction of those who transmit the virus to others. The purpose of the review, which focused on current UK law and policy, was to formulate a position paper for consideration by the UK Department of Health and the Home Office. The paper paid special attention to the public health implications of criminalization and the effect it would have on the spread of HIV within the UK population.

Results: The Terrence Higgins Trust concluded that while there was a case for prosecuting those who purposively transmit HIV to others (in effect, using it as a weapon), public health considerations outweighed any of the arguments advanced for framing criminal liability more broadly.

Lessons Learned: The criminal law is, with very limited exceptions, an ineffective and inappropriate means of dealing with those who transmit HIV to others. Legislation that facilitates the prosecution of those who transmit HIV may have a profound and damaging impact on attempts to limit the spread of infection within the population.

Presented by Matthew Weait, The Terrence Higgins Trust, 52-54 Grays Inn Road, London WC1, England.

Abstract 44113: The Crime of HIV Transmission

Issues: What is the role of laws that criminalize the spread of HIV? What is their impact on other HIV/AIDS public health measures, and on the human rights of people with HIV/AIDS?

Project: The Australian Federation of AIDS Organisations' Legal Project has contributed to policy and law reform on criminal laws against HIV transmission since 1989. This project examines: the national policy context of laws that criminalize the transmission of HIV in Australia; the rationale for, and content of, criminal laws against HIV transmission in Australia; prosecutions under Australian law; relevant international human rights instruments.

Results: Australia's experience with these laws suggests: (1) They conflict with a human rights–based response to the AIDS pandemic. (2) Australian national policy guidelines are not being followed. (3) In the second half of the 1990s, the view that criminal laws against the transmission of HIV are necessary has gained currency. (4) The number of prosecutions under such laws has increased. (5) Prosecutions are generally the subject of intense media interest.

Policy developed at a national level quickly loses currency. Australia has enacted laws that contravene its national policy. Laws that criminalize the spread of HIV are justified by their proponents in terms of the punitive role of the criminal law, and as educative tools. Such laws pose a threat to human rights and to an effective response to the AIDS pandemic.

Presented by Christopher Ward, Australian Federation of AIDS Organisations, P0 Box 876, Darlinghurst, NSW, Australia.

Abstract 44112: Evaluating the Legal Impacts of, and Responses to, AIDS

Issue: An understanding of the role of the law is crucial in an effective AIDS program.

Project: Laws in Hong Kong directly or indirectly linked with the prevention, care, and control of HIV/AIDS were reviewed. These were analyzed in conjunction with newspaper reports of related court cases in a six-year period between 1992 and 1997.

Results: The first case of AIDS in Hong Kong was reported in 1985. So far, no laws have been specifically enacted in response to AIDS. As far as disease control is concerned, the legal instrument is relatively inconspicuous. The legal responses can however be clearly inferred from the enactment and amendments of other laws. An obvious one was the amendment of the Crimes Ordinance to decriminalize homosexuality, which has led to promotion of AIDS education in the gay community. The same Ordinance has, in a complex way, also affected the pattern of commercial sex and drug use. Condom standards, an important element in safer-sex promotion, received its legal backing through the enactment of the Consumer Goods Safety Ordinance in 1995. In countering discrimination, the recently enacted Disability Discrimination Ordinance covers HIV/AIDS specifically. No case has, however, been brought to court so far. Further, AIDS impacted on the pattern of crimes in some unexpected ways. Among these were three drug users who injured or threatened to injure others with blood-filled syringes. There were instances in which the subject of AIDS was brought into courts: two prisoners applied for their sentence to be reduced because of their HIV status; on two other occasions, the judge ordered an HIV test on the defendant, which ran contrary to the policy advocated in the community.

Lessons Learned: In Hong Kong, AIDS has caused changes to existing laws and affected the enactment of new ones. The impact should not be ignored despite the low HIV prevalence. The potential impact of the judiciary's response is an area of concern.

Presented by Shui Shan Lee,[1-2] Conrad Kui Shing Lam,[2] WK Tso,[2] TMY Choi.[2]

[1]AIDS Unit 5/F Yaumatei JCC 145 Battery Street, Yaumatei Kowloon; [2] Advisory Council on AIDS, Hong Kong.

Abstract 44106: Legal Reform in Mozambique, an Opportunity to Introduce Protective Laws for PLWHA

Issue: The right to privacy of information, right to work, right to dignity and respect were being violated in Mozambique when the first AIDS cases became public knowledge. As a country emerging from thirty years of upheaval, war, and political instability, and with most legislation dating from the Portuguese colonial era, work started in 1990 on law reform. Protection of human rights of people with HIV/AIDS and AIDS patients is observed where possible.

Project: Review of existing national legislation concerning the protection of human rights of citizens with HIV/AIDS was done. As no laws were found, a study was done to define the areas of intervention.

Results: As no single law can cover all areas where people with HIV/AIDS are being discriminated against, and law reforms are being done on a global scale in Mozambique, various intervention areas were defined such as labour law, family law and law of succession, commercial law, and medical deontology. Decreasing direct discrimination against people with HIV/AIDS, empowerment of women and assuring laws to empower and protect women and children are focus points. Laws for protection of labour rights and social services for civil servants with HIV/AIDS exist now. However, it is more difficult to oblige private companies to assure social services for their workers, as they are still struggling for economic survival in a post-war economy. Review of family and succession laws is starting. Here guarantees for women will be introduced: equal rights concerning issues such as inheritance and property rights. Seeing there is no medical board in Mozambique, rules to manage HIV tests, explicitly prohibiting compulsory tests, and conditions to guarantee confidentiality are imposed. Controls on sterilization of needles, syringes and other hospital equipment, and quality control of blood transfusion must be enforced. Reforms of the penal code on violence against women and children are proposed and laws for protection of people with HIV/AIDS will be included.

Lessons Learned: The lack of existing laws to protect the human rights of people with HIV/AIDS at the beginning of this project did not prevent us from defining the areas of need and launching interventions. Legal reforms are an opportunity to introduce laws to assure that Mozambicans with HIV/AIDS may enjoy a minimum set of protective laws in the future, to ensure a dignified life, a basic human right of every person born in this world.

Presented by Avertino Barreto,[1] Brigitte de Hulster,[2] A Pinto.[3]

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[1] Ministry of Health, National STD/AIDS Program, CP 264 Maputo; [2] TA of Commission of European Communities, Maputo; [3] Ministry of Justice, Maputo, Mozambique.

Abstract 44115: The Value of HIV Anti-Vilification Laws: Test Case Outcomes

Issue: Anti-vilification laws are said to provide an enabling environment legislatively and socially for HIV prevention and promotion of human rights. Such laws prohibit public conduct that incites hatred of people with HIV. What have anti-vilification laws contributed to HIV/AIDS prevention, how effective are such laws, how are they perceived by the community, and what place do they have in preventing discrimination and violence against people with HIV?

Project: Conduct of a test case, the first of its kind in Australia, and review and analysis of the media coverage the decision received.

Results: The complainant was awarded $50,000 in damages and a public apology. The case generated significant national media coverage. This case was an opportunity to promote anti-vilification laws and to counter views that such laws provide “special rights” or are impediments to “free speech.”

(1) Anti-vilification laws are likely to come under increasing threat as Australia’s political environment becomes more conservative. The recent emphasis on “free speech” has enabled the expression of previously unacceptable views. It was essential to anticipate perceptions of the case, and to emphasize the “free speech” defence in the legislation. (2) There are significant disincentives to using such laws, including stress and delays.

Presented by Julia Cabassi, AIDS Council of NSW, P0 Box 350, Darlinghurst NSW2O1O, Australia.

Abstract 475*/44126: Ethical vs Moral Duties when HIV/AIDS Clinical Trials End

Background: People with HIV/AIDS have limited accessibility to clinical care in developing countries due to high costs. In particular, high-quality primary-care services (PCS) are not generally available.

Methods: A multicentre, prospective clinical trial for chemoprophylaxis of tuberculosis was conducted in Mexico City from December 1993 to October 1997 on non-pregnant adult, HIV-1 positive, Karnofsky scale above 60 percent, PPD positive subjects. Three clinical sites were established for follow-up of participants for administration of study drugs, periodical CD4+ counts, surveillance for adverse effects, and six-month visits for documentation of endpoints. Clinical care was provided within a non-governmental organization. Funding from the National Institutes of Health (USA)/Panamerican Health Organization and Mexican Ministry of Health supported the project. Informed consent was obtained from participants.

Results: 181 patients were recruited and followed for an average of 40.4 months. Participation in the clinical trial represented the only option for PCS for 149 patients (82 percent). Participation in the study provided participants with “warm” clinical care, routine indicators of disease progression, and advisory and referral for specialized care. 91 patients (50 percent) were referred to secondary/tertiary care for provision of antiviral treatment and diagnosis and treatment of opportunistic diseases. Most participants will not have access to these PCS after conclusion of the clinical trial. National and international ethical regulations were followed.

Conclusions: Unfortunately we are not able to ensure continuation of quality PCS for participants. We have not been successful in enrolling subjects in another clinical trial. Although ethical regulations have been followed and scientific purposes have been achieved, we, as investigators, feel frustrated as we consider that a moral commitment is established with participants that goes beyond legal aspects. Moral obligations within clinical trials, beyond ethical and scientific issues, should be discussed.

Presented by Jose Luis Valdespino Gomez,[1] ML Garcia Garcia,[2] M Palacios Martinez,[2] L Ferreyra Reyes,[2] ME Mayar Maya,[2] ME Jimenez Corona,[2] M Ramos Madrigal.[3]

[1] Ave Universidad 655, Cuernavaca Morelos CP 62508; [2] Instituto Nacional De Salud Public Cuernavaca MOR; [3] Fundacion Mexicana De Lucha Contra El Sida, Mexico.

Abstract 471*/44123: Additional Unethical Aspects of Vertical Transmission Studies in Developing Countries

Issues: After the publication of the ACTG 076 study, which demonstrated that zidovudine caused a two-thirds reduction in HIV transmission from pregnant women to infants, attention turned to identifying an affordable regimen for developing countries. In April 1997, we identified a total of 15 studies involving over 17,000 developing-country women that sought to identify such regimens (eg, regimens using zidovudine for 4-6 weeks antepartum) by providing placebos or interventions not yet proved effective to at least some women. We initiated a campaign, both in medical journals and in the popular press, to redesign the studies so that all women had access to at least some antiretroviral drugs. So far, one study in Ethiopia has been redesigned to eliminate its placebo group.

Project: To determine whether the studies violate additional ethical guidelines.

Results: There are three additional unethical aspects to these studies: (1) The informed consent form in at least one study fails to state that a pre-planned sub-analysis of data from ACTG 076 showed a two-thirds reduction in HIV transmission among women receiving an average of only seven weeks of zidovudine. (2) There is no provision for the women to continue on antiretrovirals after the study is completed, even though noncompliance with antiretrovirals (in this case, forced non-compliance due to zidovudine being unaffordable in most developing countries) is a known cause of HIV resistance. (3) There is also an observational study of 125 HIV-positive pregnant women, conducted by the Thai and US armies, Thai researchers, and Johns Hopkins University, which has continued to provide the subjects with no zidovudine even though zidovudine is so available that Thai researchers terminated their own placebo-controlled trial in January 1997.

Conclusion: The studies are unethical in a variety of ways beyond the provision of placebos. This highlights the need for the studies to be redesigned and for a renewed commitment to the conduct of ethical studies in developing countries.

Presented by Peter G Lurie, SM Wolfe, Public Citizen, 1660 20th St, NW Washington, DC, 20009, USA.

Abstract 415*/44116: Legal Provision for Clients with HIV

Issue: Discrimination is often reported in conjunction with HIV infection. A crucial way to combat such discrimination is the provision of access to redress via the law. As part of a European initiative, a study was carried out to examine legal provision for people with HIV.

Method: 11,000 UK lawyers/barristers were questioned regarding their HIV work and information needs.

Results: 600 lawyers reported a need for information on HIV and 146 had taken cases for HIV-positive clients. The 146 noted a mean of 2.2 clients (total 303) in the last year and 5.5 (total 700) previously, totaling 1003 cases. Unlike the normal process of legal cases, the majority (69.5 percent) proceeded to court/tribunal, 19.9 percent received advice only, 8.9 percent settled without action, and 1.7 percent abandoned their case. Ten percent of cases related to discrimination, 26 percent to crime, 23 percent to immigration, and 14 percent to housing. These areas of worry may reflect legal provision and access bias. Crime nearly always receives free legal-aid support and clients of necessity need to consult lawyers for crime. There was a disproportion between background epidemiology and case proportion with hemophilia-related cases having the lion's share of legal attention (41 percent of cases) followed by gay/bisexual men (20 percent), family (4 percent), women (9 percent), drug users (11 percent) and ethnic minority individuals (11 percent). Out of all the lawyers, only 18 percent had received HIV input – 67 percent would like some and 71 percent requested a helpline.

Conclusion: There is a growing need for legal assistance. Currently it is disproportionately channeled and the balance is affected by statutory provisions. Discrimination accounts for one in ten cases and lawyers note a desire for information and update.

Presented by Avrom Sherr,[1] L Sherr,[2] L Nebley,[1] J Orchard.[1]

[1] IALS, Charle Clore House, Russell Sq, London; 2 RFHSM, London, UK.

Abstract 476*/44135: Providing Care, Support and Treatment to HIV-Positive Injection Drug Users: Legal and Ethical Issues

Issue: Legal issues create barriers to appropriate care, support and treatment for HIV-positive injection drug users. In particular, service providers may be caught between legal constraints and ethical demands in providing services to injection drug users: treatment programs are highly regulated and overly restrictive, and certain treatment options, such as prescribing heroin and cocaine, are not available in most countries.

Project: We identified the legal and ethical issues raised by (1) interventions directed at providing care, treatment and support to drug users with HIV/AIDS, and (2) efforts to reduce the harms from drug use; organized a national workshop to identify four "top priority" issues that needed to be analyzed in more detail; analyzed these "top priority" issues from the perspective of ethics, law, and policy; and prepared a report that summarizes the main issues and problems raised, and proposes potential solutions.

Results: The following questions have been analyzed in detail, from the perspective of ethics, law, and policy: (1) What is the impact of the current legal status of drugs and drug use on HIV/AIDS care, treatment and support of drug users? What are possible alternatives to the current legal status? (2) What legal and ethical issues must be considered in allowing or tolerating drug use in the course of providing health care or social services? (3) Is it legal and ethical to make cessation of drug use a condition for treatment for a drug user? Is it legal and ethical to withhold antiretroviral drugs from HIV-positive drug users? (4) What legal and ethical issues are raised by prescribing opiates and controlled stimulants to drug users? For each question, potential solutions are proposed.

Lessons Learned: The current legal status of drugs and drug use creates almost insurmountable barriers to the HIV/AIDS care, treatment and support of drug users and to reducing the harms of drug use. Those providing services often observe that they "know what to do, but are not able to do it for a variety of reasons," most often legal in nature. Strong legal, ethical, and policy arguments can be developed that will assist in advocacy efforts directed at removing these barriers.

Presented by Eugene Oscapella,[0] R Jürgens,[1] D Riley,[2] D Roy,[3] T De Bruyn,[4] E Burnham.[1]

[0] 70 MacDonald St, Ottawa, Ontario; [1] Canadian HIV/AIDS Legal Network, Montréal, QC; [2] Canadian Foundation for Drug Policy, Ottawa, ON; [3] Centre for Bioethics/IRCM, Montréal, QC; [4] Consultant, Ottawa, ON, Canada.

Abstract 44143: Children Confronting HIV/AIDS: The Convergence of Rights and Prevention and Care Needs

Objectives: To develop an agenda for governmental action on HIV/AIDS in children which respects, protects, and fulfils the rights of the child.

Method: As the pandemic pursues its course, its impact on the lives of children is increasingly being felt. Infected by HIV, affected by the impact of the HIV epidemic, and vulnerable to acquiring HIV infection, infants, young children, adolescent girls and boys are confronting new challenges to their health and development. In 1990, the first human rights document to focus specifically on the rights of children – the Convention on the Rights of the Child (CRC) – came into being. States are responsible for not violating rights directly as well as for ensuring the conditions that enable us to realize our rights as fully as possible. This is understood as an obligation on the part of governments to respect, protect, and fulfill rights. While these principles are applicable to governmental obligations as they relate to every right, every person – adult or child – and every action taken, this analysis uses these obligations to consider the rights of the child as they apply to governmental action that may concern children infected, affected or vulnerable to

HIV/AIDS. This research charts the determinants of risk and vulnerability of the child to HIV/AIDS and their relationships to specific articles of the CRC within an international human rights framework.

Results: An agenda for governmental action can be created by recognizing the convergence of the three situations in which children are confronting a world with AIDS (children infected, affected and vulnerable) and the three levels of government obligations that exist for every right (respect, protect, and fulfill). This analysis sheds new light on government responsibility for ensuring that children no longer be the objects of decisions affecting them, but subjects taking part in these decisions as their capacity evolves.

Conclusion: This approach incorporates the promotion and the protection of rights of the child into the diversity of responses needed to bring the pandemic under control and mitigate its impact.

Presented by Sofia Gruskin & D Tarantola, Harvard School of Public Health, FXB Center, 654 Huntington Avenue, Boston, MA, USA.

Abstract 44187: Legislating HIV Prevention Policy: Spousal Notification Requirements in the United States

Background: In the 1996 reauthorization of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, the US Congress mandated that all states "require a good faith effort" to notify and refer for HIV testing all spouses of known HIV-infected individuals. A spouse was defined as any person legally married (within the ten years prior to HIV diagnosis) to an individual with known HIV infection. States were required to certify to the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration that they would comply with the spousal notification requirements or risk losing federal funding.

Objective: Assess the types of responses by states to the Congressional mandate.

Methods: We surveyed all 50 states, the District of Columbia, and the Commonwealth of Puerto Rico ("CARE grantees") and abstracted their reports describing actions taken in response to the legislation.

Results: Senior health officials for all 52 CARE grantees certified compliance with the requirement. All CARE grantees retained eligibility for funding. Although almost two-thirds (32 – 61.5 percent) of CARE grantees reported that spousal notification was an implicit element of their current partner notification program, many grantees undertook significant steps to assure compliance with the legislation. Seventeen grantees (30 percent) changed regulations, 40 (76.9 percent) revised protocols for staff potentially involved in identifying or notifying spouses, 44 (84.6 percent) communicated directly with private physicians and clinics regarding the new requirement, and 51 (98.1 percent) undertook special training initiatives.

Conclusion: A Congressional requirement for spousal notification that was linked to possible loss of funding had a substantial impact on public health practice in the United States. Whether the focus on legally married spouses contributed to HIV prevention efforts is unknown.

Presented by T Stephen Jones, GR West, DF Brownell, Centers for Disease Control and Prevention, 1600 Clifton Road NE Mailstop E35, Atlanta, Georgia 30333, USA.