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HIV treatments, vaccines, and microbicides: toward coordinated advocacy

In November 2003, the Canadian HIV/AIDS Legal Network convened a meeting in Montréal of global experts working in the fields of treatments, vaccines, and microbicides. The meeting was historic in that it was the first occasion on which advocates from the three fields had the opportunity to meet and exchange views on policy priorities. In this article, John Godwin provides a summary of the background paper produced for that meeting and of the key outcomes of the meeting. The article describes the reasons why developing a joint advocacy agenda has emerged as a priority for advocacy organizations from the three fields, despite their differing histories and the fact that they have often been positioned as competitors rather than collaborators. The role of a human rights approach in informing joint advocacy and the relevance of the prevention–care–treatment continuum are considered. The article then examines possible areas for joint advocacy, including funding, clinical trials, public private partnerships, tax credits, liability issues, equity pricing, bulk procurement, regulatory issues, manufacture, delivery, and national plans. The article concludes by noting upcoming opportunities for joint advocacy efforts, and outlining the next steps to be taken by the Legal Network to support coordinated advocacy.

Introduction

Until recently, treatment, vaccine, and microbicide advocates have pursued their objectives in large part independently from each other. Whereas treatment activism has been focused on the immediate imperative of scaling up access to existing treatments, vaccine and microbicide

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Canadian HIV/AIDS Legal Network

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

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

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

The Network is based in Montréal. We welcome new members. For membership information, write to info@aidslaw.ca or visit our website at www.aidslaw.ca/AbouttheNetwork/membership.htm.

Comments?

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

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EDITORIAL

In his editorial in the last issue of the *Review*, Theodore de Bruyn talked about the importance of – finally – taking action to reduce stigma and discrimination against people living with HIV/AIDS and populations affected by HIV/AIDS in Canada. He emphasized that the work needed cannot be limited to a short-term campaign and concluded that

If the [Canadian] Strategy [on HIV/AIDS] does not include plans to implement and finance action against stigma and discrimination in a sustained fashion over the next five years, Canada will have fallen short of its obligations. And the consequences will be lived in the infection, isolation, and oppression of yet more people with HIV/AIDS.¹

If anyone still needed convincing, the recent “outbreak of HIV/AIDS related stigma and discrimination” in Québec, described in this issue,² has provided yet further evidence of the fact that we need to take concerted and strategic action against stigma and discrimination.

What is happening? Since 1996, the new treatments for HIV/AIDS have changed the lives of the vast majority of people with HIV/AIDS in rich countries. The treatments often have debilitating side effects and they do not work equally well for everyone, but most people who have access to them have seen their health improve radically and their lives extended. At the same time, we have not witnessed the decrease in HIV/AIDS-related stigma and discrimination that some people were expecting would follow the decrease of HIV-related mortality. Some recent studies even seem to indicate that stigma and discrimination are on the increase. This means that many of the peo-

ple living with HIV/AIDS who are in better health cannot fully realize the potential offered by the new treatments, because they are victims of society’s attitudes toward people living with HIV/AIDS and are discriminated against in employment or other areas of their lives. In addition, other studies have shown that many people who should be on treatments are not able to access them. These are the most marginalized people living with HIV/AIDS, many of whom are injection drug users and/or Aboriginal and/or women, and many of whom have suffered from multiple stigma and discrimination for most of their lives.

It was somewhat disingenuous to think that the advent of new treatments would automatically lead to the “normalization” of HIV and to the disappearance (or at least dramatic reduction) of HIV-related stigma and discrimination. HIV/AIDS continues to affect primarily people who are not part of the mainstream of Canadian society and who are often, and perhaps increasingly, blamed for contracting HIV by those who do not consider themselves to be at risk. In addition, there are new incentives for discrimination: HIV treatments are costly, and not only employers are shying away from opening their doors to HIV-positive people who may be a great asset to their companies, but could cause increases in insurance premiums. The Canadian government itself will not allow certain HIV-positive people to immigrate to Canada based on the fact that their medical needs may create a burden on Canada’s health and social services. Finally, the number of people estimated to be living with HIV in Canada has grown by 40 percent since 1996, from 40,000 to 56,000, due to the large number of new infections yearly and to

the fact that the number of deaths attributable to AIDS has decreased dramatically. At the same time, governments have not increased their spending on HIV/AIDS, and the extent of the epidemic in Canada seems to have been largely forgotten and rarely attracts any attention by the public or in the media. Instead of increasing, the number of Canadians who are well informed about HIV, about how it is and is not transmitted, and about the reality of the lives of people living with HIV/AIDS is decreasing. Therefore, we should not be surprised that stigma and discrimination remain a problem; rather, we should ask ourselves how it is that we have not taken them more seriously and developed long-term action plans to counter them.

Unfortunately, Canada is not alone in neglecting the fight against stigma and discrimination. HIV treatments, which are currently not accessible to nearly all of the 95 percent of people with HIV who live in developing countries, may finally become more accessible there. Some commentators seem to be confident, once again, that this will automatically solve the problems of stigma and discrimination. They even suggest that HIV testing should become “routine,” meaning that everyone accessing health care would be tested for HIV unless they “opt out from testing” by explicitly refusing to be tested.

It is certainly true that access to HIV testing needs to be vastly scaled up in developing countries, and that it needs to be part of the effort to scale up access to treatment. It is also likely that stigma and discrimination in developing countries will be reduced when more people are able to know their HIV status and benefit from treatment, changing the perception that HIV is a death sentence. However, we should know better than to think that stigma and discrimination will disappear, and we should scale up efforts against them with as much determination as we scale up access to (voluntary) HIV testing and to treatment. Unless we do so, the full potential of HIV testing and treatment will not be realized, in the developing world as in Canada.

– Ralf Jürgens

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¹ T de Bruyn. Editorial. *Canadian HIV/AIDS Policy & Law Review* 2003; 8(3): 5-6 at 6.

² See the article by D. Garmaise entitled “Québec: An outbreak of HIV/AIDS-related stigma and discrimination” in this issue of the *Review*.

HIV treatments, vaccines, and microbicides: toward coordinated advocacy

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advocates have emphasized the importance of taking the long-term view and have argued for investments in research that may not see a return in terms of product availability for a decade or more.

Yet if one scratches the surface, one finds that many of the strategic policy concerns in the three fields are the same. Although working to different time frames, advocates have a common interest in promoting innovative research into products designed for use in resource-poor settings, and in addressing access issues (such as expanding access to existing products, and putting in place measures to support rapid and equitable access to new products). Having recognized the common agenda emerging around these issues, the Legal Network is seeking to promote coordinated advocacy among the three fields.

The Network's initiative had its genesis in a satellite meeting of the XIV International AIDS Conference, Barcelona 2002, which focused on treatments and vaccines for developing countries.¹ That meeting voiced agreement that vaccine and treatment advocates should advance a joint agenda on overlapping policy concerns, and that a dialogue should be initiated with microbicide advocates to explore commonalities. To take this idea forward, in 2003 the Network developed a project called HIV Treatments, Vaccines and Microbicides: Developing an Agenda for Action, to explore the intersecting agendas of the fields and to foster coordination between advocates. The work of the project has included preparing a background paper and

convening an international expert consultation in Montréal in November 2003.²

We need new treatment and prevention options

A unifying factor for advocates is their commitment to broadening the range of options available to fight HIV. Globally, there are very few social environments in which currently deployed strategies are keeping HIV/AIDS in check. In the prevention sphere, difficulties are being encountered even in wealthy low-prevalence settings, as education and behaviour-change efforts confront a complex range of social and behavioural challenges. In the treatment field, side effects, drug resistance, and treatment failure are reminders that we need new and better ways to manage HIV disease. Cheaper and simpler treatment regimens, as well as monitoring tools and diagnostics, are urgently required to facilitate treatment scale-up in resource-poor settings. Research and development (R&D) efforts in the vaccine, treatments, and microbicide fields hold great promise of delivering powerful new tools for fighting the epidemic.

The prevention-care-treatment continuum

Underpinning an emergent common agenda is the recognition that prevention, care, and treatment form a continuum and represent essential and interrelated elements of a comprehensive response.

Treatment supports prevention. Where treatments are available, rates of onward transmission are likely to

be reduced as the lowering of viral load in individuals on treatment makes the transmission of HIV on average less likely per risk incident. Hence, where antiretroviral (ARV) therapies are readily available across a population, there may be a public health benefit in terms of reduction of HIV incidence. And there is evidence from ARV treatment pilots that a reduction in stigma and increase in HIV testing rates associated with expanded treatment access support behavioural prevention efforts because people are more willing to know their status and access prevention services.³

A reduction in stigma and increase in HIV testing rates associated with expanded treatment access support behavioural prevention efforts.

Extending this logic, vaccine and microbicide advocates point out that the relationship of new prevention technologies to treatments is also potentially mutually reinforcing. The conduct of large-scale vaccine and microbicide trials in low- and middle-income countries presents opportunities to build health-care infrastructure, train laboratory and clinical staff, and improve and expand treatment services for communities hosting trials.

It's a two-way street: treatment access provides a supportive social

context for rolling out new prevention products, while investing in health infrastructure and training to bring expanded access to treatments can enhance the capacity to trial and eventually deliver vaccines and microbicides. This has been the experience in Brazil, where the process of building laboratory, health-care, and community infrastructure to enable access to treatments is providing a basis on which vaccine and microbicide trials are able to proceed. Treatment access programs strengthen the health sector, as health-care workers gain skills, community confidence in services is generated, and there are reduced losses of health-care professionals to HIV illness. A strong health sector that is accessible to and supported by local communities is important for trialling and delivering new prevention products.

Further, the product categories themselves are interrelated. HIV vaccine research is likely to lead to the development of both therapeutic and preventive products. Some microbicide candidates incorporate ARVs as preventive agents. Trials of the use of ARVs by HIV-negative high-risk populations are commencing in 2004, in the hope that ARVs will prevent HIV transmission much like a vaccine. Distinctions between the product categories are increasingly blurred.

A human rights approach

The human rights approach provides a conceptual framework for linking advocacy in the three fields. It reminds us that prevention and treatment advocates pursue a common goal – the achievement of the highest attainable standard of health for both people living with HIV/AIDS and HIV-affected communities.

A rights framework implies a unified vision of treatment and preven-

tion goals that is inclusive of vaccines, microbicides, and treatments, and that recognizes the importance of continued support for existing prevention measures such as education and harm reduction. This concept was explored in detail by the 2002 Consultation on the UN's International Guidelines on HIV/AIDS and Human Rights. The Consultation led to the publication of Revised Guideline 6 on Access to Prevention, Treatment, Care and Support, which requires states to

take measures necessary to ensure for all persons, on a sustained and equal basis, the availability and accessibility of quality goods, services and information for HIV/AIDS prevention, treatment, care and support, including antiretroviral and other safe and effective medicines, diagnostics and related technologies for preventive, curative and palliative care of HIV/AIDS and related opportunistic infections and conditions.⁴

A rights approach also reminds us that the success or failure of R&D and scale-up efforts must be measured from a pro-poor, community-oriented perspective. Important aspects of a rights-based approach include:

- an emphasis on participation of communities in decisions affecting their rights;
- the universality of rights, in that they are intended to be enjoyed by everyone without discrimination;
- the responsibility of states to transfer the benefits of scientific progress and its applications to assist less wealthy nations in realizing the right to health;
- the concept of progressive realization of the right to health; and
- the centrality of the role of states in assuring public health and addressing epidemic diseases.

Legal obligations of states to respect, protect, promote, and fulfil human rights, including the right to health, derive from international law (principally the Universal Declaration of Human Rights⁵ and the International Covenant on Economic, Social and Cultural Rights⁶), regional human rights agreements,⁷ and some national laws.⁸ International commitments to the full realization of human rights related to HIV/AIDS are articulated in the UN's Declaration of Commitment on HIV/AIDS,⁹ in General Comments of the UN Committee on Economic, Social and Cultural Rights,¹⁰ and in resolutions of the UN Commission on Human Rights on the right to the highest attainable standard of health and access to medication.¹¹

While recognizing the unifying power of a rights-based approach, advocates at the 2003 Montréal consultation noted the challenges faced in advocating for a rights agenda in countries where a human rights culture remains underdeveloped, or in fora where priorities are determined by market interests, such as negotiations on free-trade agreements, rather than human rights.

Constructing an agenda

Research and clinical trials

Advocates have a common interest in arguing for enhanced programs of publicly funded basic research. Breakthroughs in areas such as virology and immunology stand to benefit treatment and prevention fields alike.

Building the capacity of countries to conduct large-scale clinical trials is a high priority for vaccine and microbicide researchers, given the large cohorts required to demonstrate the efficacy of preventive technologies in phase III trials. Building trial capacity will also facilitate trials of treatment

strategies, such as simplified treatment regimens, designed specifically for resource-poor settings.

Much work has been done in the last few years to define the ethical issues involved in conducting research in developing countries, notably the guidance on vaccine ethics provided

Advocates in all three fields have a common interest in arguing for enhanced programs of publicly funded basic research.

by the Joint United Nations Programme on HIV/AIDS (UNAIDS).¹² Mutual benefits would be gained from sharing practical approaches adopted in trials to issues such as informed consent, use of placebos, confidentiality, and standard of care for trial participants.

Advocates from all fields need to assess the impact of new research initiatives, with a view to recommending how they may be better coordinated and expanded. Major new programs include the European and Developing Countries Clinical Trials Partnership and the US National Institutes of Health's (NIH) Comprehensive International Program of Research on AIDS. Advocates have a common role in encouraging community involvement and transparency of trial programs. Advocates might focus on developing mechanisms for community participation in trial processes through community advisory or management input mechanisms, and identifying education and training requirements to support community participation. Measures to ensure that

trial participants' rights are protected, such as participants' bills of rights,¹³ may be another focus for advocacy.

A significant concern for those conducting trials is competition for site capacity. Dialogue among global players on a system for according priority access to trial sites is desirable. In the vaccines field, a Global HIV Vaccine Enterprise has been proposed that would bring the major global players in vaccine R&D together to prioritize the scientific challenges to be addressed, to prioritize product development efforts, and to engage in implementation planning.¹⁴ This proposal draws from the approach of the Human Genome Project, which involved many funders agreeing on a scientific road map, voluntarily dividing the work, and agreeing to production standards. There may be lessons to be learned from this for collaborative planning of HIV R&D more generally.

Participants at the Montréal consultation concluded that advocates should explore common community participation issues as a priority, and formed an informal working group to examine opportunities for collaboration. Prevention and treatment fields face common community-engagement, preparedness, recruitment, and retention challenges. To date, community-preparedness efforts tend to be ad hoc and product-specific. The three fields also face common epidemiological, social, and behavioural research needs, and similar challenges regarding long-term follow-up of research participants.

Funding

Advocates have a common interest in advocating for a better global funding deal for R&D, one that is responsive to the health needs of poor communities rather than being market driven.

Prevention-technology R&D is drastically underfunded, and research into treatments is dominated by private-sector interests. Donors need to be reminded that the Global Fund to Fight AIDS, TB and Malaria (the Global Fund) does not fund R&D and that product development initiatives therefore need direct donor support.

To supplement the work of the Global Fund, the Commission on Macroeconomics and Health recommended in 2001 that another fund be established to finance research on diseases of the poor.¹⁵ The Montréal consultation expressed the concern that because there continue to be difficulties in raising money for the existing Global Fund, it may be unwise to try to create another distinct research fund. The consultation concluded that it may be more useful to focus on fundraising for existing product development initiatives.

The Global Fund is supporting a range of treatment access initiatives. Enhanced treatment access and the strengthening of primary health-care delivery systems through Global Fund-supported projects will potentially result in significant benefits for vaccine and microbicide developers, in terms of both trial and delivery issues.

The Montréal consultation concluded that it would be useful for advocacy purposes to provide a cost estimate for global HIV R&D needs for all three fields, coupled with related scaling-up costs. This is based on the need to bring multiple products into phase III trials at the same time as scaling up treatment provision in trial communities. The consultation also called for greater support to the Global Fund, given its role in treatment scale-up and support for health systems development. As well, the consultation highlighted the importance of

debt relief for poor countries with underdeveloped health systems.

Purchasing and financing mechanisms

Structures need to be put in place to enable countries with similar needs and buying power to negotiate good prices when procuring health products. Establishing bulk-procurement mechanisms for ARVs is an important strategy to keep prices down. The World Health Organization (WHO) is currently investigating procurement mechanisms to help achieve its target of treating three million people by 2005 (3x5). Lessons from these approaches can be used to inform the bulk procurement of vaccines and microbicides as they become available.

Financing is required to ensure that poor countries are able to afford both to pay for large supplies of medicines, vaccines, and microbicides, and to invest in domestic delivery systems. One option is for the Global Fund to manage a scheme in conjunction with the World Bank and regional development banks. If the Global Fund proves successful in

Lessons from efforts to reduce the prices of antiretrovirals can be used to inform the bulk procurement of vaccines and microbicides as they become available.

guaranteeing better commodity security with existing products, it could play an important role in building the confidence of product

developers that future products will be purchased.

Another option is to establish a new international finance facility for global public health goods, linked to the Global Fund, to support treatment scale-up and to provide commitments to finance purchases of vaccines, microbicides, and other new health products. The proposal for a new finance facility to fund the achievement of the Millennium Development Goals (MDGs), which is being promoted by the UK at the G8, could play a role in this.

Pre-commitments to purchase bulk quantities of vaccines, microbicides, or new drugs could provide an incentive for private-sector R&D investment. Advocates at the Montréal consultation expressed concern, however, that while advance purchase commitments may lead to new R&D efforts, they would not necessarily result in countries actually wanting to use products. It was suggested that ensuring that the Global Fund is sustainable is preferable to focusing on purchase commitments.

Strategies for stimulating strategic R&D

Strategies for stimulating R&D include public private partnerships (PPPs), expanding public-sector roles, tax relief, and reducing liability risks. Injecting substantial new funds into public-sector R&D would provide immediate benefits for the three fields. Public bodies play very significant roles in basic research and product development, particularly in the case of products for which there is perceived to be little market incentive for private investment.

However, much of the global R&D expertise is located within the private sector. PPPs, such as those

pursued by the International AIDS Vaccine Initiative, provide effective models for harnessing this expertise. More effective PPP models could be developed through advocates examining best practices in PPPs in such areas as input by communities from the global South in partnership arrangements, and accountability and transparency mechanisms.

In the past, tax relief as a strategy to foster private-sector R&D has been promoted by vaccine advocates, and has potential benefits for the microbicide and treatment fields as well. However, it can be argued that it is more useful to invest funds directly in publicly funded research programs rather than subsidize private industry. Advocates in the US are backing away from tax credits as a strategy. Instead, pointing to the US government's recent investments in anthrax and smallpox research as a precedent, advocates are arguing for more direct incentives, such as government contracting with the private sector and public assistance with vaccine manufacturing.

Exposure to product liability lawsuits is a significant deterrent to vaccine development in litigious environments such as the US. Advocates have sought to address this by promoting no-fault compensation models that minimize exposure to risk of liability for HIV vaccine manufacturers. Vaccine and microbicide manufacturers could jointly build a public interest case, using the US bioterrorism precedent, for provisions to indemnify manufacturers from liability arising from use of HIV-prevention technologies because of the potential of these products to stem the epidemic. The Montréal consultation pointed out that in addressing liability issues, it is important to ensure that consumer

rights to compensation are not unduly eroded, particularly where consumers are relatively powerless, such as in poor communities.

Patents

Patent issues remain high on treatment access agendas, as indicated by ongoing debates about the World Trade Organization (WTO) TRIPS¹⁶ Council's position on the capacity of countries to import generic medicines.¹⁷ This issue is due to be considered again at the WTO's 2004 meeting.

Although clearly a priority issue for treatment advocates, obtaining a satisfactory resolution to the generic-medicines issue should also be viewed as a matter of concern for vaccine and microbicide advocates. Flexible patent rules that encourage generic competition, and that are responsive to the health and development needs of poor countries, are a common goal. The Montréal consultation pointed out that trade agreements with the US that require compliance with "TRIPS plus" provisions (provisions that go beyond what the WTO rules require) can result in the exclusion of generic competition in developing-country markets for extended periods and that advocates from the three fields therefore need to monitor trade agreements closely.

Advocates also have a common interest in investigating open collaborative intellectual property models, drawing, for example, from the experience of SARS research, the Human Genome Project, the Global Positioning System, and open source software. The World Intellectual Property Organization is considering convening a meeting in 2004 to consider such models, and the US NIH is increasingly supportive of open drug-development models.¹⁸

Equity pricing

Rapid implementation of differential pricing for essential medicines as a global norm has the potential to support treatment scale-up and to provide a framework for future HIV vaccines and microbicides to be made available at low cost.

The UNAIDS/WHO Accelerated Access Initiative makes ARVs available at reduced prices in poor countries by negotiating with manufacturers. The disadvantage of this approach is that it has resulted in ad hoc, country-by-country reductions and has not provided a systemic solution. Desirable features of a differential pricing approach are structures that ensure sustainability and set prices for poor markets as close as possible to direct costs of production. Voluntary approaches to differential pricing remain the preferred option of G8 governments. The G8 Evian summit health action plan refers to the G8's support for "pharmaceutical companies' voluntary long term commitments to provide essential medicines at substantially discounted prices."¹⁹

Differential pricing has to be placed in the context of a range of options to achieve affordability.

The Montréal consultation noted that differential pricing has to be placed in the context of a range of options to achieve affordability. Licensing of generics and legislated price controls are proving more effective than voluntary differential pricing

in supporting treatment scale-up in contexts such as South Africa. Initiatives to negotiate discounted bulk supplies of generics, such as those achieved by the Clinton Foundation, and the strategies being pursued through the WHO's 3x5 initiative, may mean that differential pricing of brand-name products is less important as a treatment access strategy. The consultation concluded that it was important for advocates to work together to support price transparency – for example, through a mandatory system for the monitoring and reporting of global prices of therapeutics, diagnostics, and preventive technologies for HIV.

Regulatory issues

Streamlining regulatory requirements is important to reducing delays in approving trials and to licensing new products. Most developing countries have only a limited regulatory infrastructure. The lack of regulatory capacity in the South means that approval of products for marketing is often heavily influenced by the decisions of the US Food and Drug Administration (FDA) and the European Agency for the Evaluation of Medical Products.

A pathway to licensure for products designed for use only in the developing world needs to be defined. Vaccine and microbicide advocates have pointed out that a partially effective HIV vaccine or microbicide, which might not be approved by regulators in the US or Europe because the efficacy level is considered too low, could nonetheless be highly appropriate for use in countries with rapidly emerging epidemics. This indicates the need to provide a new framework to extend the mandate of Northern regulators so that they can make decisions based

on the needs of developing countries, rather than just Northern markets.

UNAIDS, the WHO, and the FDA need to be supported in expanding their roles in the provision of financial assistance and technical advice to countries to ensure informed national regulatory decision-making. Efforts to strengthen national regulatory infrastructure should be prioritized in countries where clinical trials are being conducted, and in countries that are well placed to play a regional leadership role (for example, Thailand and South Africa). Harmonization of regulatory measures may reduce the need for trials to be repeated in multiple countries. Countries with similar epidemiological and population characteristics could benefit by pooling their regulatory expertise and linking approval processes.

WHO prequalification of therapeutics and vaccines is providing developing countries without strong regulatory capacity with a reliable process for assessing products. The Montréal consultation concluded that WHO initiatives, such as its prequalification process, should be pursued with greater urgency and expanded both because they can support treatment scale-up and because they may prove useful for future HIV vaccines and microbicides.

Manufacturing

The lack of manufacturing capacity is a major factor in the lengthy delays in getting pharmaceutical products to market in the South. This issue may become even more significant as the focus of product development shifts to small biotechnology companies and non-profit organizations that do not have the capacity to invest in manufacturing. Substantial private- and public-sector invest-

ments in manufacturing will be required to meet global demand for an HIV vaccine or microbicide. The public sector needs to demonstrate a willingness to assist the private sector in managing the risks involved in creating sufficient capacity to meet projected demand. Scaling up manufacturing capacity will necessitate a better understanding of potential demand for products which, in turn, needs to be based on a better understanding of the potential impact of different products in different epidemiological contexts.

The Montréal consultation concluded that advocates have a common interest in advocating for a program of financial assistance to support investment in manufacturing facilities in the global South. An initial focus may be to build the capacity of countries with some level of existing pharmaceutical manufacturing infrastructure.

Delivery

The usual pattern has been for rich countries to enjoy access to new health technologies years in advance of developing countries. This is not an acceptable model for HIV treatments, vaccines, or microbicides. Improving delivery systems for existing treatments, vaccines, and contraceptives is key to preparing for the delivery of new products. Treatment activists have helped to provide the environment in which access to new therapies is seen as a consumer right. The continued vibrancy of this movement may be critical to generating local support for the rapid rollout of vaccine and microbicide products as they become available.

Delivery issues for vaccines and treatments will likely overlap, given the involvement of medical staff in

prescribing, dispensing, and administering products. There are many intersecting health-promotion issues, given the need to develop coherent messages that educate communities about the health benefits of each product. Communities will need to understand the implications of partially effective vaccine and microbicide products, and the need to sustain condom use and other prevention strategies. Research will be required to assess consumer attitudes to products, the likely demand

The Montréal consultation emphasized the crucial role of community mobilization in supporting delivery.

for product uptake, and consumer responses to partially effective prevention products.

The Montréal consultation emphasized the crucial role of community mobilization in supporting delivery, and noted the potential for integrated community education programs to address: (a) the mutually supportive relationship of treatments, vaccines, and microbicides; and (b) issues specific to partially effective products.

National plans

National planning is a key strategy for ensuring political support for vaccines, microbicides, and treatments. Countries need to start contingency planning now to enable vaccine and microbicide delivery systems to be operational as soon as possible after new products are licensed.

The Montréal consultation reviewed plans already developed in

Uganda, Thailand, and Brazil, and concluded that important elements of national plans include:

- a human rights framework;
- commitment to the participation of community representatives in the planning process;
- recognition of the links between prevention and treatment; and
- consideration of the impact of trade agreements on domestic public health priorities.

The Montréal consultation concluded that it is important for national plans to reflect a comprehensive response that considers the interrelationship of vaccines, microbicides, and treatments, and agreed that advocates should develop a checklist of desirable elements for inclusion in national plans relating to R&D and access to new treatment and prevention technologies.

Opportunities to advocate the agenda

A number of opportunities for advocacy were identified, and the Montréal consultation agreed to work toward a common action plan to guide advocacy efforts in the period 2004-2006. The consultation stressed that global policy interventions would fail unless they are supported by policy work at the national and local levels. Convening three-way meetings of advocates at the national level was proposed as one way of ensuring that advocacy priorities could be set locally as well as through action at global and regional levels.

WHO patents review

The World Health Assembly agreed in May 2003 that the WHO would establish a "time-limited body" to review

patent issues and incentive mechanisms for the creation of new products against diseases that affect developing countries, and that the body would report by January 2005. Advocates could benefit by agreeing on proposals to be put to the WHO review, either independently or through joint proposals.

G8 summits

The 2003 G8 resulted in a disappointing health action plan. Advocates should coordinate their efforts to ensure that the 2004 and 2005 summits result in more concrete outcomes. Joint proposals targeting the host US and UK governments for these summits should be prepared well in advance and with broad cross-sectoral support, including from UN agencies.

The UN Millennium Project

The UN MDGs are highly significant in informing the priorities of global donors. The UN's recommended strategies for achieving the MDGs will influence the major global bilateral and multilateral agencies. As well, the MDGs are the central point of reference for discussions about financing development. UN action on the MDGs can be influenced through input to the UN's Millennium Project, which is due to report to the UN Secretary-General in mid-2005, and through the UN Conference on Trade and Development XI, to be held in São Paulo in June 2004.

UN Special Rapporteur on the Right to Health

The UN Special Rapporteur on the Right to Health, Paul Hunt, is conducting a three-year investigation from 2002 to 2005. It may be beneficial for advocates to present a joint

plan of action to the Rapporteur on priority measures that the UN system might undertake in order to promote access to new health technologies. The Montréal consultation agreed that Paul Hunt would be alerted to the existence of the action plan being developed by advocates.

UN Declaration of Commitment on HIV/AIDS compliance reporting

Performance indicators were developed by UNAIDS in 2002 for use in monitoring progress toward achieving targets established by the Declaration of Commitment. Countries are required to report progress periodically to UNAIDS using the indicators. It would be useful to develop more precise indicator sets to monitor R&D and access measures relating to vaccines, treatments, and microbicides.

International convention on R&D

Public health goods might benefit from agreements similar to those used to put human genome research into the public domain. Treatment advocates have begun to promote the need for an international convention, treaty, or trade agreement on health R&D that would commit countries to contribute to health R&D, provide an equitable basis for sharing the cost burden of R&D, and establish mechanisms for exchanging research results and transferring technology.

The Montréal consultation noted the importance of this proposal, although there was a difference of views regarding the utility of a convention solution. The Global Forum for Health Research, to be held in Mexico in November 2004, may be an appropriate forum for exploring global agreements.

International and regional HIV/AIDS conferences, 2004-2006

International AIDS conferences (Bangkok 2004, Toronto 2006) and regional conferences provide an opportunity to publicize and build support for a consensus agenda on R&D and related access issues. The media attention the global conferences attract is an opportunity for joint media work on a single issue of agreed priority, such as highlighting successes in combining treatment scale-up strategies with prevention trials.

Next steps

The Montréal consultation agreed to support the development of a Statement of Commitment from advocacy organizations, which will set out a commitment to advocate for a comprehensive HIV response, principles to guide joint advocacy (such as a human rights approach and the prevention–care–treatment continuum), and top-line priorities for joint action. A plan of action that sets out opportunities for joint advocacy for the 2004-2006 period will also be developed. The Canadian HIV/AIDS Legal Network is playing a coordinating

role for these initiatives. A satellite meeting to follow up on the issues raised at the consultation will be held at the XV International AIDS Conference in Bangkok in July 2004.²⁰

– John Godwin

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¹ The satellite was organized by the Legal Network, the AIDS Law Project (South Africa), and the Lawyers Collective (India), and co-hosted by UNAIDS.

² The background paper was funded by the International AIDS Vaccine Initiative (IAVI); the global consultation meeting was funded by UNAIDS, the WHO–UNAIDS HIV Vaccine Initiative, IAVI, the International Partnership on Microbicides, Health Canada, and the Canadian International Development Agency.

³ T Kasper et al. Demystifying ARV therapy in resource-poor settings. *Essential Drugs Monitor* No 32, 2003.

⁴ Office of the High Commission for Human Rights/UNAIDS. *HIV/AIDS and Human Rights International Guidelines: Revised Guideline 6: Access to prevention, treatment, care and support*. Geneva: UNAIDS 2002, at 14.

⁵ Articles 25(1) and 27(1).

⁶ Article 12. The right to health can also be derived from a range of other international treaties and covenants, eg, Convention on the Rights of the Child, Article 24; Convention on the Elimination of All Forms of Discrimination Against Women, Articles 11 and 12.

⁷ African Charter on Human and Peoples' Rights, Article 16; American Convention on Human Rights in the Area of Economic, Social and Cultural Rights, Article 10; European Social Charter, Article 11.

⁸ Over 60 nations include health rights in their constitutions: P Hunt. *Report of the Special Rapporteur on the Right*

to Health. Report to the 59th Session of the Commission on Human Rights, February 2003, at 7.

⁹ Article 55.

¹⁰ See *General Comment 14: The Right to the Highest Attainable Standard of Health*. Doc E/C, 12/2000/4.

¹¹ 2001/33, 2002/32, 2003/29.

¹² *Ethical Considerations in HIV Preventive Vaccine Research: UNAIDS Guidance Document*. Geneva: UNAIDS, 2000; *The Ethics of Research Related to Healthcare in Developing Countries*. London: Nuffield Council on Bioethics, 2002 (available at www.nuffieldbioethics.org/publications); *Ethical and Policy Issues in International Research: Clinical Trials in Developing Countries*. Bethesda, MD: National Bioethics Advisory Commission, 2001 (available at www.georgetown.edu/research/nrcbl/nbac/pubs.html); *International Ethical Guidelines for Biomedical Research Involving Human Subjects*. Geneva: Council for International Organizations of Medical Sciences (CIOMS), 2002.

¹³ Eg, South African Preventive HIV/AIDS Vaccine Trial Participant Bill of Rights (www.saavi.org.za/bill_of_rights.htm).

¹⁴ R Klausner. The need for a Global HIV Vaccine Enterprise. *Science* 2003; 300(5628): 2036-2039.

¹⁵ *Report of the Commission on Macroeconomics and Health: Investing in Health for Economic Development*. Geneva: WHO, 2001, at 192.

¹⁶ TRIPS refers to the WTO's Agreement on Trade-Related Aspects of Intellectual Property Rights.

¹⁷ See R Elliott. TRIPS from Doha to Cancún ... to Ottawa: global developments in access to treatment and Canada's Bill C-56. *Canadian HIV/AIDS Policy & Law Review* 2003; 8(3): 1, 7-18.

¹⁸ See discussion of models at www.cptech.org/ip/health3/rndtif/.

¹⁹ Online via www.g8.fr/evian/english/home.html by clicking on "Health – A G8 Action Plan."

²⁰ These documents, as well as a report that introduces the issues and incorporates feedback from the meeting, will be published in English, French, and Spanish in 2004. All documentation is available on the Legal Network's website at www.aidslaw.ca/Maincontent/issues/vaccines.htm.

CANADIAN NEWS

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

Québec: An outbreak of HIV/AIDS-related stigma and discrimination

In the space of a few weeks in January 2004, actions by three different institutions in Québec combined to threaten the human rights of people living with HIV/AIDS, raise the spectre of mandatory HIV testing, and create unnecessary public fears about the spread of HIV infection. In response to what they called “the worst weeks in recent history for people living with HIV/AIDS in Québec,” the Canadian HIV/AIDS Legal Network and COCQ-Sida (the Québec coalition of community-based organizations fighting AIDS) called for a province-wide campaign against HIV/AIDS-related stigma and discrimination.¹ A victory was achieved when a Montréal catholic seminary announced that it had backed down from its initial proposal to mandatorily test all applicants for priesthood for HIV, but much more is needed to fight the rapid outbreak of mandatory-testing proposals.

The three institutions involved were the Grand Séminaire de Montréal, the Ste-Justine Children’s Hospital, and the City of Montréal.

Grand Séminaire

On 10 January 2004, the Grand Séminaire de Montréal, a Catholic

seminary, announced that as of September 2004, all applicants for the priesthood would be required to undergo HIV testing.²

Initially, the Grand Séminaire linked the HIV testing policy with homosexuality. It said that the new policy did not mean that HIV-positive

applicants would be automatically excluded, but that they would be required to explain how they got infected. If they were infected as a result of homosexual activity, the Grand Séminaire said, they would have to convince the administration that they were serious about their religious vocation.³ Marcel Demers, the rector of the Grand Séminaire, said that homosexual applicants would not be automatically refused, but that their chances of being accepted were minimal.⁴

Then, the Grand Séminaire claimed that homosexuality had nothing to do with it. At a news conference on 12 January, the Archbishop of the Diocese of Montréal, Cardinal Jean-Claude Turcotte, said that “homosexuality is not a criterion.” The issue, he said, was the “health of

the candidates” and their “[physical] capacity to fulfil their duties.”

Cardinal Turcotte said that the priesthood was “a lifelong project” and that “AIDS is a serious illness that can cut short the life of a person.”⁵

Cardinal Turcotte said that the Grand Séminaire was not the only Catholic seminary to require HIV testing. He said that HIV testing was mandatory at seminaries in Edmonton and Vancouver, in many US states, and in Africa.⁶

Reaction

The Grand Séminaire policy was denounced by numerous gay and HIV/AIDS organizations. A representative of the Association gay anonyme pour prêtres exclusivement (AGAPE), a group of gay Catholic priests that works within the church, characterized the policy as “excessive” and said that if he were planning to enter the Grand Séminaire today, he would have to think twice about it. Gilles Marchildon, Executive Director of Égale Canada, a gay rights organization, said that the policy would “further stigmatize people living with HIV/AIDS by making them unwelcome within the church.” Robert Rousseau, of Séro Zéro, an AIDS service organization, said that the policy sends a dangerous message of exclusion.⁷

On 13 January, the Canadian HIV/AIDS Legal Network and COCQ-Sida wrote to Cardinal Turcotte to protest the new policy.⁸

On 14 January, the Québec Human Rights Commission said that it would examine whether it should launch an investigation into the matter. Commission spokesperson Ginette l’Heureux said that the church may be contravening the Québec Charter of Human Rights and Freedoms if the purpose of asking for the test is to

check the person’s state of health. An employer can discriminate on the basis of a person’s handicap if it prevents the person from carrying out the job, she said, but there is nothing inherent in HIV that prevents a person from saying mass or carrying out other priestly duties.⁹

On the same day, the Legal Network and COCQ-Sida wrote to the Québec Human Rights Commission strongly urging the Commission to launch an investigation.¹⁰ In that letter, the two organizations said that “the decision by the Grand Séminaire de Montréal to ask applicants for priesthood to submit to an HIV test can have a negative impact on Québec society, by promoting discrimination against all people ... living with HIV/AIDS.” The letter went on to say:

Submitting applicants to an HIV test cannot be justified.... [U]nder Canadian law, no employer has the right to impose mandatory pre-employment HIV testing, and it is also against the human rights laws of all provinces to demand such information because to do so amounts to discrimination based on disability. The human rights acts also do not in any way provide an exemption to the Catholic Church that would allow it to demand pre-employment HIV testing of potential employees. Under article 20 of the Québec Charter of [Human] Rights and Freedoms a distinction or exclusion might not be discriminatory if it is based on a “qualification required for an employment” or is “justified by the religious nature of a non-profit institution.” But clearly being HIV-negative is not a necessary ... requirement to be a priest, and the archdiocese has a duty, like all other employers, to accommodate any employee with a disability (be it HIV or something else). And there is nothing in the “religious nature” of the Church that would provide any justification or requirement to only hire HIV-negative priests.

HIV is not a barrier to fulfilling the duties of priesthood. HIV-positive people can and do lead long, healthy lives. It is often not their HIV-positive status, but society’s discrimination that makes it impossible for them to make a full contribution – which is exactly why they continue to need protection against the types of discrimination non-voluntary HIV testing opens the door to, and why it is so important for the Commission to launch an investigation.

The decision by the Grand Séminaire and the public statements by Cardinal Turcotte perpetuate stigma and misinformation about HIV and people with HIV. All Quebecers living with HIV have received a slap in the face from an institution that should practice what it should preach: respect and inclusion. The decision and the public statements have been widely reported in the media – in fact, no other story on HIV has received as much coverage in the media in recent history. The message that people risk taking from it is that it is OK to exclude people with HIV because they are incapable of fully participating in the activities of life. We

The decision by the Grand Séminaire and the public statements by Cardinal Turcotte perpetuate stigma and misinformation about HIV and people with HIV.

are concerned that we will see an increase in discriminatory practices against people with HIV if the Commission does not launch an investigation.

The Human Rights Commission agreed to consider the request to launch an investigation.

On 15 January, the Legal Network and COCQ-Sida issued a news release reiterating the points raised in the letter to the Human Rights Commission. “The consequences of HIV antibody testing continue to be different from many other medical tests,” said Lise Pinault, Executive Director of COCQ-Sida. “No doubt, there are significant benefits to people who undergo voluntarily HIV testing. They can access treatment if they are HIV positive, and take steps to prevent HIV transmission. However, if the HIV test is not entirely voluntary and undertaken with appropriate counselling, it can be used to unjustly discriminate against people, to exclude them from full participation in society, based on false notions about HIV and people with HIV.” Ralf Jürgens, Executive Director of the Legal Network said, “In 2004, discrimination against people with HIV/AIDS in Canada remains pervasive, and we cannot allow further injustice to happen.”¹¹

The Legal Network prepared opinion pieces that were published in both *Le Devoir* and the *Toronto Star*.¹² The Network also wrote to Archbishop Raymond Roussin in Vancouver and Archbishop Thomas Collins in Edmonton to urge them to reconsider their HIV testing policies for seminarians.

Ste-Justine Children’s Hospital

On 22 January 2004, officials of the Ste-Justine Children’s Hospital called a news conference to announce that it was recommending that 2614 patients be tested for HIV infection because it had just learned that a surgeon who operated on these patients was HIV-positive. The hospital did not name the surgeon, who died in 2003. However, media sources disclosed that the surgeon was a woman and also pub-

lished her name.¹³

Dr Lucie Poitras, Director of Professional Services at the hospital, said that the risk of HIV transmission to the patients during surgery was “extremely weak ... almost non-existent.” Khiem Dao, the hospital’s Executive Director, said that the hospital was nevertheless recommending that the patients be tested because “children’s safety takes priority over all other considerations.”¹⁴

Dr Poitras said that the surgeon informed her immediate supervisor in 1991 that she was HIV-positive, and that a committee was formed to determine “what kind of medical work [the surgeon] could do.”¹⁵ However, the hospital was unable to find any records of the committee’s deliberations after 1996.¹⁶

Reaction

Some media commentators expressed shock that an HIV-positive physician was allowed to operate on a patient; others claimed that any risk (no matter how low) that could lead to the transmission of a serious or deadly disease should be disclosed to patients prior to treatment.¹⁷ In some media reports, there were calls for mandatory testing of physicians.

Philippe Couillard, the Québec Minister of Health and Social Services, said that HIV-positive doctors should disclose their condition to hospital directors, but that mandatory HIV testing of physicians would be “legally dangerous.” He said that HIV testing could violate privacy laws and the Québec Charter of Rights and Freedoms. “It raises numerous questions regarding confidentiality,” he said, “and testing can create a false sense of security.”¹⁸

Couillard pointed out that the surgeon “took very strict precautions when she acted on patients.” He said

that the real issue in this case is that “after 1996, there was no proper follow-up in the institution.” He also noted that the Québec College of

Deep public fears particular to HIV and AIDS should not drive public policy.

Physicians was working on a disclosure policy for doctors with contagious illnesses.¹⁹

In an editorial published on 27 January, the *Montréal Gazette* argued against mandatory testing of surgeons.

[M]edical professionals are best suited to provide guidance on such questions. Deep public fears that are particular to HIV and AIDS should not drive public policy.

Experts say the risks of HIV transmission from surgeon to patient, if established protocols are followed, are so low [that] systematic and recurrent testing of surgeons would be a waste of money. In the U.S. about 25,000 people who had been operated on by HIV-positive surgeons have been tested, and not one was HIV-positive. There have been only two known infections of this kind in the entire world. Greater patient protection might well be achieved by testing surgeons for influenza, checking their blood-alcohol count, or not letting them operate if they haven’t had, say, six hours of sleep.

And who, exactly, should be tested? Why test surgeons but not nurses ... or orderlies? How often should all these people be tested? Weekly? And since HIV transmission from patient to doctor is much more common than vice-versa, should all patients be tested, too? Ultimately, the question becomes: Should everybody who provides or

receives a medical service be tested? We think not.

It's instructive to remember the example of the late Quebec-born surgeon Lucille Teasdale, who safely treated 39,000 people in her Ugandan clinic in the 15 years after she contracted HIV from an injured soldier. After being diagnosed, she was advised by her own London doctor the public interest was best served by her continuing to do surgery. She took precautions and continued, as did ... the Ste. Justine's surgeon....

[The Ste-Justine surgeon] did the ethically right thing by reporting her illness to her surgical supervisor in 1991, and the supervisor did the right thing by creating an internal "expert committee" to monitor her health and work, in accordance with Quebec College of Physicians guidelines.²⁰

The *Gazette* editorial went on to say that shortcomings in the hospital's oversight system need to be corrected.

On 2 February, Philip C Hébert, a family physician and bioethicist at Sunnybrook and Women's College Health Sciences Centre in Toronto, and Philip B Berger, chief of the Department of Family and Community Health at St Michael's Hospital in Toronto, said in an opinion piece in the *Toronto Star* that the hospital's actions have "naturally caused much worry for [the patients'] families." The physicians went on to say that

[t]he risk of HIV transmission from physician to patient is of extremely low magnitude – lower than many risks we accept daily. HIV will be passed on from an infected surgeon to his or her patient once in every 10 million encounters. The risks of almost everything we do are more common than this....

If physicians had to disclose everything with a 1 in 10 million risk, we

would never get through the day. For example, both authors of this article have notoriously bad handwriting. Should they warn their patients about the serious hazards of illegible handwriting (which are likely greater than 1 in 10 million)?

This would mean that almost any less than optimal condition – just the physician having a bad day might qualify – would have to be disclosed to the patient. Requiring disclosure of all conditions potentially affecting physicians would paralyze patient decision-making....

The rule for consent in Canada is to tell patients what a "reasonable person" would want to know. In our view, anything with less than a one in a million chance of occurring is so remote as not to require disclosure to a reasonable person.... [T]he way to protect the public is not to impose an impossible rule of disclosure. The best way is to ensure that physicians ill with conditions that might affect their ability to work safely have access to confidential advice and medical care.

In the case of the HIV-infected surgeon, it is reasonable to require reporting to a medical board that could independently assess the health practitioner's fitness to practise. This will protect patient and practitioner alike.

In the matter of patient safety, the physician's competence and professionalism are paramount – not his or her HIV status. No ethical physician would knowingly place a patient at risk of avoidable harm. Maintaining the privacy of HIV-infected health-care providers can be reasonably balanced against the right of patients to know of potential harm.²¹

Also on 2 February, following consultations with its members, the Québec Medical Association (QMA), a division of the Canadian Medical Association, came out in favour of a disclosure and monitoring process

within health-care institutions for physicians infected with HIV, but said that it objected to systematic screening of physicians. Dr André Senikas,

Maintaining the privacy of HIV-infected health-care providers can be reasonably balanced against the right of patients to know of potential harm.

President of the QMA, said that "When a physician is infected, whether with HIV or another pathogenic infection, decisions affecting the physician's right to work should be based on professional self-regulation, as well as on the best scientific data available, and not on political or emotional considerations."²²

The QMA also called for universal precautions to protect both patients and physicians.

City of Montréal

The Canadian Press said in a story on 24 January 2004 that new recruits for the Montréal Police Force will be tested for HIV starting 1 March 2004, and that candidates who test positive for HIV will not be hired. In the article, Peter Yeomans, who is the City of Montréal executive committee member responsible for public security, cited "public security" as one of the reasons for the policy. "A police person is called into emergency situations where there is obviously injuries, open lesions," he said.²³

In the Canadian Press story, Yeomans suggested that money was also a concern. In another article a few days later, Yeomans provided the

following explanation for the policy: “We want to protect the employee and the public – it’s a public health issue. We’re looking at a 30-year proposal here; we want to bring people into the force and work right to retirement.”²⁴

Reaction

In a news release issued on 26 January, the Legal Network and COCQ-Sida pointed out that all members of the police forces take “universal precautions” to protect themselves and others while on their job. It makes no sense to suggest that new recruits need to be free from HIV, the organizations said. They added that this could soon lead to proposals that all members of the police forces be regularly tested for HIV and other infectious diseases, such as hepatitis – which is not necessary and would therefore be discriminatory.²⁵

Keith Monteith, Executive Director of AIDS Community Care, a Montréal AIDS service organization, said that “to exclude someone from a job who’s going to be able to function for many, many years” is discriminatory and is giving in to public fears. “I don’t see how [HIV-positive members of the force] can transmit HIV to someone during the course of their work,” Monteith said, “considering they know how to take precautions.”²⁶

The Québec Charter of Human Rights and Freedoms prohibits discrimination on the basis of a disability. The Québec Human Rights Commission explicitly recognizes HIV as a disability. “Health tests cannot be ordered unless they are directly related to the job,” said Commission spokesperson l’Heureux. She said it was up to the employer to prove that testing is directly related to the job and that an illness prevents the person from doing the work. “We can’t discriminate against someone who is not

in perfect health,” l’Heureux said.²⁷

On 29 January, the *Gazette* reported that a survey it undertook of associations representing dentists, nurses, restaurants, and ambulance crews revealed that none of them require that applicants for jobs be tested for HIV.²⁸ However, Peter Yeomans was later quoted as saying that HIV testing should be considered for other public employees; he named ambulance technicians and firefighters as examples.²⁹

Call for a campaign against stigma and discrimination

On 26 January 2004, in light of the events at the Grand Séminaire, the Ste-Justine Children’s Hospital, and the City of Montréal, the Legal Network and COCQ-Sida issued a second joint news release, calling on the Québec government to fund a province-wide campaign against HIV/AIDS-related stigma and discrimination.³⁰

“First, all Quebecers living with HIV received a slap in the face from Cardinal Turcotte, when he made public statements defending the decision to ask all priesthood applicants to undergo HIV testing, and suggested that HIV-positive people would not be able to fulfill the duties of priesthood,” said Ralf Jürgens. “Then, there have been calls for mandatory HIV testing of health-care workers, despite 20 years of consensus that this is not the best way to protect patients, and despite the minimal risk of HIV transmission from health-care providers to patients. And finally, Peter Yeomans ... irresponsibly suggested that applicants for Montreal’s police need to be free from HIV to be able to do their job,” he added.

“We are shocked by how little people in power and ordinary Quebecers seem to know about HIV and people

with HIV, and by their willingness to exclude them. The government has an

The government has an obligation to counter the stigma and prejudices.

obligation to counter the stigma and prejudices,” said Lise Pinault.

“Between 14,000 and 22,000 people in Québec are believed to be living with HIV or AIDS (out of a total of 56,000 in Canada). Because of new treatments, the majority of these people are living longer and in better health,” Jürgens added. “It is ignorant to suggest that HIV-positive people cannot be employed and fully contribute to society.”

The Legal Network and COCQ-Sida also wrote to Minister of Health Couillard to formally present their call for a province-wide campaign.³¹

Grand Séminaire backs down

The actions of the Legal Network, COCQ-Sida, and others quickly produced results on one of the fronts. On 16 February 2004, the Archdiocese of Montréal issued a statement saying that it had rescinded its plan to require that applicants to the Grand Séminaire undergo HIV testing.³²

Ginette l’Heureux of the Québec Human Rights Commission expressed satisfaction with the announcement, saying “I think they’ve reflected on this and have been enlightened.” Ralf Jürgens said, “This seems to indicate that they got the message that this would have been illegal.... For us, the statement is a positive one.... We hope that they are acting in good faith.”³³

While the community can take some satisfaction that its actions produced positive results, the events at the Grand Séminaire, the Ste-Justine Children's Hospital, and the City of Montréal clearly demonstrate that HIV/AIDS-related stigma and discrimination are still very much alive in Canada and that a well-organized response is required to deal with the problem.

– David Garmaise

¹ Canadian HIV/AIDS Legal Network, and Québec Coalition of Community-Based Organizations Fighting AIDS (COCQ-Sida). AIDS and human rights organizations say no to HIV testing based on ignorance and prejudice. News release, 26 January 2004. Available at www.aidslaw.ca/Media/press-releases/e-press-jan2604.htm.

² D Parkes. Catholic seminary to screen for HIV. *The Gazette*, 10 January 2004.

³ Les tests de dépistage du sida pour les prêtres sont critiqués. *Radio Canada*, 11 January 2004.

⁴ *Supra*, note 2.

⁵ F Deglise. Grand Séminaire de Montréal – Dépister le VIH dans une logique de "transparence." *Le Devoir*, 13 January 2004.

⁶ *Ibid.*

⁷ *Ibid.*

⁸ The letter is available at www.aidslaw.ca/francais/Contenu/themes/tests/Lettre_CardinalTurcotte.pdf.

⁹ D Parkes. Seminary's demand for HIV test may violate rights: commission. *The Gazette*, 14 January 2004.

¹⁰ The letter is available at www.aidslaw.ca/Maincontent/issues/testing/Lettre_HIVTestCQDPJ.pdf.

¹¹ Canadian HIV/AIDS Legal Network, and Québec Coalition of Community-Based Organizations Fighting AIDS (COCQ-Sida). HIV testing of priesthood candidates called illegal and unethical. News release, 15 January 2004.

¹² R Jürgens. Rappel au cardinal Turcotte et autres intéressés – Quelques rudiments du test du VIH. *Le Devoir*, 16 January 2004; R. Jürgens. A refresher course on HIV testing. *Toronto Star*, 20 January 2004. Both articles are available at www.aidslaw.ca/Media/archivedreleases.htm#pcl.

¹³ P Ray. Montreal Ste-Justine Children's Hospital will test 2,614 patients for HIV. *Canadian Press*, 22 January 2004.

¹⁴ *Ibid.*

¹⁵ *Ibid.*

¹⁶ L Lévesque. Quebec Medical Association adopts disclosure policy for HIV-positive doctors. *Canadian Press*, 5 February 2004.

¹⁷ P Hébert, P Berger. Dealing with surgeons and HIV. *Toronto Star*, 1 February 2004.

¹⁸ HIV-positive docs should advise their hospitals: Québec health minister. *Canadian Press*, 26 January 2004.

¹⁹ *Ibid.*

²⁰ HIV: Public safety doesn't require HIV testing. *The Gazette*, 27 January 2004.

²¹ *Supra*, note 17.

²² Québec Medical Association. The QMA supports an internal disclosure process. News release. Available at www.amq.ca/ang/pri_nou_commu.htm#6fevrier2004.

²³ New Montreal police recruits will be tested for HIV after March 1. *Canadian Press*, 24 January 2004.

²⁴ 1 Block. Montreal police alone in HIV test. *The Gazette*, 29 January 2004.

²⁵ *Supra*, note 1.

²⁶ S Banerjee. City's ban on HIV-positive cops disputed. *The Gazette*, 28 January 2004.

²⁷ *Ibid.*

²⁸ *Supra*, note 24.

²⁹ D Parkes. Seminary won't test for HIV. *The Gazette*, 17 February 2004.

³⁰ *Supra*, note 1.

³¹ The letter is available at www.aidslaw.ca/Maincontent/issues/testing/E-letter_to_health_minister.PDF.

³² Catholic Archdiocese of Montréal. The Archdiocese of Montreal continues its reflection but excludes the imposition of H.I.V. test. News release. Available at <http://diocesemontreal.org/accueil/langues/>.

³³ *Supra*, note 29.

Alberta: New bill will allow for mandatory HIV testing in emergency situations

A private member's bill is expected to be introduced in the spring 2004 session of the Alberta Legislative Assembly that will allow for forced testing of individuals for HIV, hepatitis, and other blood-borne diseases if their bodily fluids come into contact with emergency workers or Good Samaritans. The bill will likely have strong support from within the ranks of the governing Conservatives.

According to an article in the *Calgary Herald*,¹ Edmonton Conservative MLA Thomas Lukaszuk is expected to introduce legislation that will force individuals to undergo tests for HIV, hepatitis, and other bloodborne diseases if their bodily fluids come into contact with those of a police officer,

corrections officer, other emergency workers, or Good Samaritans. The private member's bill is set to be introduced in the spring 2004 session of the Alberta Legislative Assembly.

Lukaszuk said there are numerous instances of emergency workers being spat at, bitten, stuck with needles, or exposed to other bodily fluids from persons they may be dealing with. Under the proposed legislation, testing could be required if a person refuses to give a blood sample. The order would need to be approved by a medical officer of health, and information obtained from the blood test could not be used in any criminal proceedings or for any purpose other than to determine if the emergency workers affected require medical treatment. Lukaszuk said that unlike similar legislation that came into force in Ontario last September,² his bill will

not include testing to protect victims of crime. He said that it would be impossible to obtain a timely sample from an individual who first has to be proven guilty or not guilty.

Lukaszuk's bill is expected to receive broad support from the Conservative caucus. It also has support from police and emergency services groups. The bill is in response to cases such as the January 2001 incident in which Calgary Police Service Constable Ray McKenzie was bitten on the hand by an HIV-positive man during an arrest. Following the bite, the suspect had shouted, "Welcome to the world of AIDS." Constable McKenzie immediately underwent drug treatments, and has continued to test negative for HIV.³

HIV/AIDS experts have argued that implementing mandatory testing would not protect workers from occu-

pational exposures, and that other measures – such as education, training, and counselling – would be more effective. They also argue that mandatory testing infringes on the rights of the individual being tested.⁴

– Rebecca Scheer

¹ K Cryderman. Alberta may force AIDS tests to protect emergency workers. *Calgary Herald*, A1, 23 January 2004.

² See M Perry. Ontario proclaims blood samples legislation, delays privacy bill. *Canadian HIV/AIDS Policy & Law Review* 2003; 8(1): 27-28; also, R Carey. Ontario adopts "blood samples" legislation. *Canadian HIV/AIDS Policy & Law Review* 2002; 6(3): 39-40.

³ There was a similar incident in Edmonton in 2002. See R Scheer. Spitting incident leads to renewed calls for mandatory testing. *Canadian HIV/AIDS Policy & Law Review* 2002; 7(2/3): 36.

⁴ See T de Bruyn and R Elliott. Compulsory HIV testing after an occupational exposure. *Canadian HIV/AIDS Policy & Law Review* 2002; 6(3): 1; 24-31; also, T de Bruyn. Occupational Exposure to HIV and Forced HIV Testing: Questions and Answers. Montréal: Canadian HIV/AIDS Legal Network, 2002. Available at www.aidslaw.ca/Maincontent/issues/testing/testing-q&aE.pdf.

Media frenzy greets release of Newfoundland man from prison

Sensationalist media coverage greeted the release of a man convicted more than a decade ago for spreading HIV in Conception Bay North. Concerns have been expressed that the extensive coverage of the release will further stigmatize all people living with HIV/AIDS.

The release from prison of a man convicted 11 years ago of criminal negligence causing bodily harm for knowingly infecting two women with HIV received extensive media cover-

age in Newfoundland and Labrador. The media took their cue from a statement released by the RCMP, the headline of which read "RCMP Warns Public: Dangerous Offender Returns

to Province." Media coverage warned about the potential consequences of releasing this dangerous offender back into society, especially since it was rumoured that he may return to his home community in Conception Bay North.

Radio stations, television, and newspapers scrambled for statements and the AIDS Committee of Newfoundland

and Labrador received numerous requests for comments. News programs put together interviews with a variety of experts who could speak about the topics at hand, including an interview with the man himself entitled “Sex, Lies and HIV.”¹ The media ensured that his name and face were ones that all Newfoundlanders and Labradorians could instantly recognize. Suddenly HIV/AIDS was getting a lot of airtime, not as part of an awareness campaign, but as a public safety issue.

It seemed that the media were anticipating a repeat of the early 1990s, when considerable public attention was focused on the outbreak of HIV in Conception Bay North. In the words of one local resident: “It took a long time to live down the stigma the media generated when all this first happened years ago. Now they are starting it again.”

Individuals across the province had differing opinions concerning the release of the prisoner, but they were particularly concerned about how the residents of Conception Bay North were coping. “There were a lot of wounds out here from what he did,” said one woman. “He brought back a

lot of memories, but the community as a whole handled it well and it didn’t cause the trouble that the media tried to create. They worked themselves into a frenzy, I really think they overdid it.”

Concerns were raised about the purpose served by the excessive media coverage. As the man was deemed to be a dangerous offender, the police were required to notify the public about his release. But the media coverage went far beyond that and may have promoted fears that extend beyond this specific incident. It is difficult to know whether the public perceived this as the act of one individual or if the media ultimately portrayed HIV as the villain. As one resident said, “I’m glad they showed his face. If he is a dangerous offender people need to know. But I’m afraid they made the public scared of everyone with HIV.” This may indeed be what happened if one can judge from the words of a caller to a popular Newfoundland radio program who said, “There should be a list composed of all AIDS infected people.”²

One of the arguments cited against the criminalization of HIV is

the fear that outlandish media attention afforded to stories such as these will further stigmatize those living with HIV/AIDS. Many people will passively process the information they see and hear without giving it a second thought. Without an analysis or understanding of the issues, all people with HIV/AIDS can be considered potential criminals.

Service providers have suggested that the time and money spent to cover this story could have been more effectively used to provide public education, harm reduction, or policy development. Unfortunately, until this happens, incidents such as the release of the Newfoundland man will continue to make top news stories.

– Michelle Boutcher

Michelle Boutcher is the Acting Executive Director of the AIDS Committee of Newfoundland and Labrador. She can be reached at mboutcher@acnl.net.

¹ The interview was on *The Docket*, CBC Television, on 23 October 2003.

² *Open Line*, VOXM Radio, 24 October 2003.

Health Canada makes marijuana available for medical use

Health Canada has finally (but reluctantly) begun to distribute marijuana for medical use, but concerns have been expressed about the quality of the product. In response to a court order, Health Canada has also made some changes to the Marijuana Medical Access Regulations (MMAR), but the changes do not fully incorporate the direction provided by the court.

In response to a court order, Health Canada has begun distributing marijuana to patients with HIV/AIDS and other medical conditions. Health Canada has also made changes to the MMAR, the regulations governing the

legal production and use of marijuana for medical purposes. The changes were made after Health Canada's appeal of the court order was rejected by the Ontario Court of Appeal.¹

Distribution to patients

Four years ago, Health Canada commissioned Prairie Plant Systems, Inc, to cultivate medical marijuana in an abandoned mine in Flin Flon, Manitoba.² Ever since, there has been controversy concerning what the crop was to be used for. Despite initial indications that at least some of the final product was slated for direct use by patients, Health Canada has opposed its distribution for that purpose, and has maintained that the crop is intended solely for clinical research.³

In a January 2003 court ruling in the case of *Hitzig v Canada*, Health Canada was ordered to provide a legal source of marijuana for individuals authorized to use it under the MMAR.⁴ On 9 July 2003, Health Canada announced an interim plan to use the Flin Flon crop to address this requirement.⁵

On 25 August 2003, the first patients received their shipments. Jari Dvorak, a Toronto man with HIV who is legally entitled to use marijuana under the MMAR, was one recipient. Although Dvorak characterized the quality of the cannabis as mediocre, he said that it was nevertheless a significant day for medicinal marijuana users nationwide.⁶

While many community advocates applauded the Canadian government for taking this step, many recipients echoed Dvorak's concerns about the quality of the cannabis – some actually claiming that it made them physically ill.⁷ Barrie Dalley, a

52-year-old Toronto man who uses marijuana to combat the nausea associated with AIDS, said, "It made me nauseous because I had to use so much of it. It was so weak in potency that I really threw up."⁸

The cannabis was criticized for its high proportion of stems and inert matter. As well, Phillippe Lucas, spokesman for Canadians for Safe Access (CSA), a medical marijuana users' collective,⁹ said that the crop "has only about three percent THC – not the 10.2 percent advertised – and contains contaminants such as lead and arsenic,"¹⁰ due to soil contamination in and around the abandoned mine where the marijuana is grown. However, Brent Zetl of Prairie Plant Systems rejected the CSA claims and said that they were "tantamount to slander."¹¹

Changes to the MMAR

When Health Canada announced the distribution plan, it stressed that the provision of marijuana to patients was an interim measure. The same day, Health Canada launched an appeal of the Ontario Superior Court decision that necessitated the distri-

The appeal court ordered that many of the restrictions in the Regulations be eased, particularly those governing production.

bution scheme.¹² That appeal was resolved on 7 October 2003, when the Ontario Court of Appeal upheld

the original Ontario Superior Court decision. The appeal court ordered that many of the MMAR restrictions be eased, particularly those governing production.

In response, Health Canada announced that "amendments to the MMAR will ... be carried out in two phases. The first phase focuses on the response to the court decision, giving national effect to certain elements of the remedy granted by the court.... The second phase will involve a broader review of the MMAR to address issues expressed by stakeholders and will incorporate a comprehensive consultative process."¹³

The first phase of the revisions to the MMAR became effective on 17 December 2003. Some, but not all, of the appeal court's directions were incorporated in the changes.¹⁴ The most notable change is that designated growers, who may legally grow marijuana for patients unable to do so themselves, may now receive financial compensation for their services. However, the changes do not implement the court's direction that (a) designated growers be allowed to produce for more than one user, and (b) that more than three designated growers be allowed to combine their efforts at one site.

Consultations on the second phase of MMAR amendments were scheduled for spring 2004.

Legal status of marijuana

During the extended debate over the constitutionality of the MMAR, legal uncertainty has surrounded simple possession of marijuana for non-medical purposes. During the period between 31 July 2001 and 7 October 2003, due to the precedent set by two cases, *JP* and *Barnes*,¹⁵ it was

unclear whether laws against possession could be considered universally valid. (The appeal court ruling of 7 October rendered possession without a medical exemption unambiguously illegal.¹⁶)

In a direct response to this uncertainty, on 9 December 2003 the Justice Department announced that it would stay proceedings against every person charged with marijuana possession during the time that the legal status was unclear. As a result, approximately 4000 cases stemming from charges laid between these dates were dismissed.¹⁷

In related developments:

- Marijuana went on sale in Dutch pharmacies on 1 September 2003, as the Netherlands made prescription marijuana available to patients.¹⁸ Dutch doctors are allowed to prescribe marijuana for a variety of conditions, including cancer, AIDS, and multiple sclerosis. The cannabis is grown by two licensed companies regulated by the health min-

istry, and is distributed to patients through regular pharmacies.¹⁹

- The Canadian Naturopathic Association has officially supported the use of marijuana for medical purposes.²⁰
- An insurance company has covered a claim for medical marijuana expenses.²¹

¹ See G Cruess. Ontario court affirms that medical marijuana regulations are unconstitutional. *Canadian HIV/AIDS Policy & Law Review* 2003; 8(3): 53-56. See also, eg, K Makin. Ottawa's pot rules unconstitutional. *Globe and Mail*, 7 October 2003.

² See J Gold, R Elliott. Medical marijuana and the law: recent developments. *HIV/AIDS Policy & Law Review* 2001; 6(1/2): 9-11.

³ See D Thaczuk. Troubled times for Canada's medical marijuana program. *Canadian HIV/AIDS Policy & Law Review* 2003; 8(1): 22-23.

⁴ See G Betteridge. Marijuana Medical Access Regulations unconstitutional because they do not provide for legal source or supply of marijuana. *Canadian HIV/AIDS Policy & Law Review* 2003; 8(1): 57-60.

⁵ See D Thaczuk. Health Canada unveils plan to distribute marijuana for medical use. *Canadian HIV/AIDS Policy & Law Review* 2003; 8(2): 20-21.

⁶ T Brautigam. Toronto man expresses relief as he picks up medicinal pot from doctor. *Canadian Press*, 26 August 2003.

⁷ D Beeby. First tokers of Health Canada cannabis call it disgusting, want money back. *Canadian Press*, 15 September 2003.

⁸ Ibid.

⁹ The CSA website is at <http://safeaccess.ca>.

¹⁰ Supra, note 7. See also: Lab tests reveal Health Canada government weed weak. *medicalmarihuana.ca*, 15 September 2003 (www.medicalmarihuana.ca/govtpot.html).

¹¹ D Beazley. Government pot grower stung by critics. *Edmonton Sun*, 17 September 2003.

¹² Supra, note 4.

¹³ Regulations Amending the Marijuana Medical Access Regulations, *Canada Gazette Part II*, Vol 137, No 26, pp 2982-2994. Available at <http://canadagazette.gc.ca/partII/2003/20031217/pdf/g2-13726.pdf>.

¹⁴ The MMAR and other related information can be found on the website of the Office of Cannabis Medical Access at www.hc-sc.gc.ca/hecs-sesc/ocma.

¹⁵ See G Betteridge. Possession of cannabis legal for now. *Canadian HIV/AIDS Policy & Law Review* 2003; 8(1): 61-62.

¹⁶ Court makes pot possession illegal again. *Canadian Press*, 7 October 2003. See also: J Rupert. Court eases medical marijuana rules, reinstates law against possession. *Ottawa Citizen*, 8 October 2003.

¹⁷ K Lunman. Ottawa stays pot charges in 4,000 cases. *Globe and Mail*, 9 December 2003.

¹⁸ Dutch start selling medicinal marijuana. *Globeandmail.com* (Associated Press), 1 September 2003.

¹⁹ P Gallagher. Netherlands OKs marijuana for medical use. *National Post*, 2 September 2003.

²⁰ Canadian Naturopathic Association supports medical marijuana. *medicalmarihuana.ca*, 25 September 2003. Available at www.medicalmarihuana.ca/cna.html.

²¹ Cannabis covered as prescription drug by insurance company. *London Free Press*, from *Canadian Press*, 18 November 2003.

AIDS in the workplace: a program that's still relevant

A new AIDS-in-the-Workplace program being implemented in Québec emphasizes the rights of workers living with HIV/AIDS. The program tackles issues such as confidentiality of HIV status, access to insurance benefits, discrimination, and the need for employers to take reasonable measures to accommodate the disabilities of workers.

In November 2003, after a program manager was hired, COCQ-Sida (the Québec coalition of community-based organizations fighting AIDS) launched its new AIDS-in-the-Workplace program (the program). The goals of the program are: (1) to promote and

defend the rights of people living with HIV/AIDS in the workplace; and (2) to prevent HIV transmission and to inform people about modes of transmission and issues relating to HIV/AIDS in the workplace. To achieve these goals, activities to be undertaken were formulated in terms of six priority areas: (1) information, education, and training; (2) support for COCQ-Sida member organizations; (3) crisis intervention; (4) research; (5) advocacy; and (6) partnerships.

The program was launched in 1988.¹ Over the years it underwent many changes, additions, and adaptations as HIV/AIDS evolved – in medical terms, of course, but also in terms of how open (or not open) society was to people affected by HIV/AIDS.

In 1992, the Ministère de la santé et des services sociaux du Québec (MSSS) relaunched the program² and in 1999 entrusted full management of it to a committee that was a member of COCQ-Sida (the committee). One of the program objectives was to sensitize managers of private, public, and semipublic enterprises to HIV/AIDS issues, in order to encourage them to adopt policies on HIV/AIDS in the workplace that would enable them to better confront the issue.

After four years, taking into account the findings that emerged from past practices, the committee decided, with the agreement of the MSSS, to reorient the program and to redirect energies to the defence of the rights of people living with HIV/AIDS. The relevance of this reorientation is demonstrated by the current situation, which leaves no doubt whatsoever as to the presence of taboos, stigmatization, and igno-

rance with respect to HIV throughout workplaces in Québec.

For example, the beginning of 2004 witnessed priesthood candidates at the Grand Séminaire de Montréal being asked to submit to an HIV test; media hype around the contacting of 2614 children operated on by an HIV-positive surgeon at Ste-Justine hospital; the City of Montréal's decision that all police recruits submit to an HIV test and that those testing positive would not be hired; the statement of Peter Yeomans, the City of Montréal executive committee member in charge of public security, to the effect that it should be possible to use HIV tests for other groups of public employees, such as ambulance technicians and firefighters;³ not to mention the

Taboos, stigmatization, and ignorance still exist in Québec workplaces.

reactions of the media and the general public to these issues (see other article in this section).

In order to deal with the issues concerning HIV/AIDS in the workplace, the following must be addressed: confidentiality; access to insurance; disability status in relation to private insurance plans, pension plans, and social assistance; non-discrimination in employment; reasonable accommodation measures by employers; and disclosure of seropositivity.

The research undertaken to date on these issues by COCQ-Sida reveals significant discrepancies between existing laws and certain

practices that have an impact on HIV-positive people who are leading, or are trying to lead, active lives.

For example, questionnaires and/or interviews may contain requests for information relating to one's state of health and, more particularly, directly or indirectly, to one's serostatus. This practice, prohibited under section 18.1 of the Charter of Human Rights and Freedoms⁴ (the Québec Charter),⁵ puts HIV-positive people into very uncomfortable and difficult situations. If a person lies about his or her HIV status and the truth later comes out, would the employer still consider that person a loyal employee?⁶ And were that person to disclose his or her seropositivity, would the person's application be considered on its merits? If it weren't, and if the person thinks that he or she has been discriminated against, would an effective remedy currently be available? Instituting legal proceedings would require disclosing one's seropositivity. In such cases, it's easy to understand that societal stigmatization and opprobrium, so hard to bear, could encourage HIV-positive people to remain silent, thereby making legal recourse a very theoretical proposition indeed.

HIV/AIDS poses significant challenges in terms of existing law and its implementation. Many problems relating to the daily lives of people living with HIV confront society with conflicting rights, and with legal responses that exist in theory but are not yet reflected in our society.

When it comes to implementing the program, the committee and the program manager at COCQ-Sida will attempt to identify grey areas in order to come up with solutions that will make a difference. The team is

convinced that this work can only be carried out by establishing partnerships with key players in the work world, such as, in particular, employers, unions, the Commission de la santé et sécurité du travail, and local job centres. Creating such partnerships is one of the program's objectives.⁷ The program currently runs from 2003 to 2005 and the decision of the MSSS to renew financing will be made following an evaluation of the program and of a number of other aspects of COCQ-Sida's work.

– Christine Vézina

Christine Vézina is in charge of the AIDS-in-the-Workplace program at COCQ-Sida. She can be contacted at christine.vezina@cocqsida.com.

¹ At the time, the federal government provided the financing and the program was managed by the Canadian Aids Society.

² In collaboration with the Ministère du travail, the MSSS published and distributed the first edition of the guide *Sida et milieu de travail: investir dans l'action* to 20,000 unionized enterprises in Québec.

³ D Parkes. Seminary won't test for HIV. *Gazette* (Montréal), 17 February 2004.

⁴ RSQ, c C-12.

⁵ The practice is prohibited unless it can be shown that seronegativity is an aptitude or qualification required for a job (section 20 of the Québec Charter). To date in Québec, no job or profession where seronegativity has been shown to be a legitimate requirement has been formally identified.

⁶ The relevance of this issue is highlighted by the fact that an employee is subject to a duty of loyalty to the employer under Article 2088 of the Civil Code of Québec (SQ, 1991, c 64). In *Roussel Canada Inc v Loubaba Cherkaoui*, [1991] CT/TT 288, the employer dismissed Ms Cherkaoui for not having been truthful, because during the hiring process (interview, signing of the work contract, medical exam), she did not inform the employer that she was pregnant. According to the employer, this was valid cause for dismissal. In its judgment, the court did not accept the employer's argument and refused to rule on the consequences of a false declaration made during the job interview. Rather, the court held that Ms Cherkaoui was under no duty to disclose her pregnancy at the time of the interview. The court thus upheld the decision of the labour commissioner that Ms Cherkaoui's dismissal was illegal because it was not based on just and reasonable grounds.

⁷ In fact, it forms a distinct component of the program (component 6 – Partnerships).

In brief

Network formed to support the implementation of UNGASS at the community level

In June 2001, 189 countries, including Canada, committed to a global response to HIV/AIDS over the next decade. This 10-year plan is known as the United Nations General Assembly Special Session (UNGASS) Declaration of Commitment on HIV/AIDS.

In an attempt to advance the use of the UNGASS Declaration of Commitment in the work being done across Canada, the Canadian UNGASS Network has been formed. It is a collective of community-based organizations, national NGOs, federal government agencies, and AIDS activists from across the country working together to implement UNGASS in Canada.

Conceptualized at the community level by Alberta AIDS service organizations (ASOs) and AIDS activists, the UNGASS Network was officially launched at the 4th Canadian Skills Building Symposium in Calgary, Alberta in November 2003. In the short time since its inception, the UNGASS Network has grown to include 13 members (at the time of writing), ranging from individuals to national groups such as the Canadian AIDS Society and government agencies such as Health Canada.

“We're thrilled with the response that the UNGASS Network has received across Canada so far in its development stage,” said Le-Ann Dolan, Community Developer at

AIDS Calgary and member of the UNGASS Network. “We hope that the momentum will continue to build, particularly at the grassroots level where the implementation of UNGASS translates into front-line action.”

The UNGASS Network aims to assist individuals and groups to implement the UNGASS Declaration of Commitment into their work, and to demonstrate that doing so can benefit them without adding significantly to their already heavy workload. A secondary aim is to bring together ASOs from across Canada to form a cohesive, grassroots group focused on ensuring that Canada continues working toward its obligation to UNGASS and increases the funding allocated to the Canadian Strategy on HIV/AIDS.

Deborah Jakubec, another UNGASS Network member, and the Peer Education Facilitator and Volunteer Program Coordinator at HIV Edmonton, said she hopes that “the UNGASS Network will be an opportunity for ASOs to work together to ensure that our government is held accountable for the commitments made in UNGASS.”

“It is important to recognize that UNGASS will not replace the work we are doing on the frontlines,” Dolan added. “In fact, it can strengthen our work in real and useful ways, and it can provide significant lobbying opportunities for increased resources for the work we do from the community level to the international stage.”

– Rebecca Scheer

If you would like further information about the Canadian UNGASS Network or would like to become a member, check the AIDS Calgary website at www.aidscalgary.org/programs/unDeclaration.shtml, or contact Le-Ann Dolan (e-mail: ldolan@aidscalgary.org; tel: 1-403-508-2500).

Guidelines on sexual health education updated

In September 2003, Health Canada published an updated version of the *Canadian Guidelines for Sexual Health Education*. The Guidelines offer clear directions to assist government bodies and local, regional, and national groups concerned with education and community health to further develop and improve sexual health education policies and programs that address the diverse needs of Canadians.

The original guidelines were developed in 1994, but had not been updated or reprinted since then. Feedback received from experts in the field at consultation meetings and focus group sessions clearly indicated the need for revisions and further additions. The publication of the 2003 Guidelines has been achieved through consultation and feedback: national meetings, surveys, and focus testing with key experts in various fields of sexual health education.

Sexual health is a major aspect of personal health that affects people at all ages and stages of their lives. In recognition of this, health promotion programs across Canada focus on enhancing sexual health and reducing sexual problems among various groups in our society.

The Guidelines are not intended to provide specific curricula or teaching strategies. They provide the

framework for evaluating existing sexual health education programs, policies, and related services available to Canadians. They are also meant to guide professionals in the development of new and effective programs that reinforce behaviours that support sexual health. In addition, the Guidelines offer educators and administrators a broader understanding of the goals and objectives of sexual health education.

The principles outlined in the Guidelines include the concept of community participation and individual choice as key components of health promotion. The Guidelines state that sexual health education is a broadly based, community-supported initiative in which the individual's personal, family, religious, and social values are taken into consideration.

— Ian Culbert

To order copies of the Guidelines, contact the Canadian HIV/AIDS Information Centre (www.aidsida.cpha.ca) or call 1-877-999-7740. An online version is available in pdf or html at www.hc-sc.gc.ca/pphb-dgspsp/publicat/cgshe-ldnemss/cgshe_index.htm.

HIV Edmonton's insurance woes send a warning signal to other ASOs

Days after AIDS Awareness Week 2003, HIV Edmonton was hit with the news that its insurer would not be renewing its professional liability, property, and event coverage insurance policy when it expired on 20 January 2004.¹ HIV Edmonton had never made a liability claim with the

insurer, only a few minor theft claims. With only three days until the insurance policy expired, and after more than 15 refusals from other insurers, HIV Edmonton finally secured a new policy with Royal and Sun Alliance Insurance Company. However, the cost of the new policy will be significantly higher.

"We were very concerned that we would have to stop our work the next week," said Sherry McKibben, Executive Director of HIV Edmonton. "We were all relieved that we were able to stay open and continue to offer our programs to our service users and the Edmonton community."²

Although the many insurance agencies gave no reasons for their refusals, the perception that HIV Edmonton has a "high-risk" clientele and is involved in activities such as a needle exchange could be the cause of the organization's insurance difficulties. "The insurance industry sees an agency like HIV Edmonton as a risk," said McKibben, "I don't know — because we're AIDS [related]?"³

"Now that we have insurance, the next challenge we face will definitely be financial," McKibben added. The new policy will cost about 4.5 times as much as the previous policy. However, it does include some expanded coverage.

Given HIV Edmonton's experience, eligibility for insurance and the rising costs of insurance may need to be added to the list of barriers that AIDS service organizations face in trying to do their work.

— Rebecca Scheer

Winnipeg partners with Kampala to fight AIDS in Uganda

In November 2003, Mayor Glen Murray announced that Winnipeg, a member of the Federation of Canadian Municipalities (FCM), would partner with Kampala, Uganda to help fight the devastation caused by HIV/AIDS. Murray, who formerly worked for an AIDS service organization, said that in addition to the city's plans to share appropriate talent and expertise, there would also be a role for institutions (such as hospitals and churches), professionals, and private and civic organizations (such as service clubs) to take part in the partnership.

The first concrete step in the partnership took place in early December. A Winnipeg delegation – including Deputy Mayor Gord Steeves, Community Services Director Ursula Stelman, and Human Resources and Corporate Services Director Bob Pruden – met the Mayor of Kampala, J Ssebaana

Kizito, in Cameroon. Stelman and Pruden subsequently went on to Kampala to meet with city officials to better get to know their partners, their municipal structures and services, and their needs. A report on this inception mission is available from Mayor Murray's office.⁴

The FCM participated in the meetings and received an award from African leaders for being their "best development partner" supporting municipal development and decentralization. The Canadian International Development Agency provides funding to the FCM to allow it to assist in the development of African municipal governments.

Kampala had a special interest in Winnipeg as a partner city because of the presence of the virology lab, the Canadian Science Centre for Human and Animal Health, in the Manitoba capital. It is considered a valuable asset that might play a role in helping Uganda cope with their AIDS crisis. It should be noted, however, that the long-term partnership being

developed will be broader than HIV/AIDS and will likely include support for activities such as developing zoning by-laws.

Some connections between Winnipeg and Kampala already exist, both in the corporate and non-governmental sectors. The next step in the partnership will involve a return mission, with Kampala city officials visiting Winnipeg likely in May or June 2004.

Other municipalities that have an interest in initiating a partnership project should consult the FCM website at www.fcm.ca for contact information.

– Roger Procyk

¹ HIV Edmonton, news release. HIV Edmonton and the Insurance Industry. 17 December 2003.

² HIV Edmonton, news release. Insurance Company Comes Through in the Crunch. 16 January 2004.

³ A Ogle. Insurance woes threaten existence of HIV Edmonton. *Edmonton Journal*, 18 December 2003.

⁴ U Stelman. Report: Inception Mission to Uganda, December 1 to 16, 2003. The mayor's website is www.city.winnipeg.mb.ca/interhom/mayors_office/mayors_office.stm.

INTERNATIONAL NEWS

This issue includes notes on developments from China to the Caribbean, and from Hungary to Zambia. Discrimination against people living with and affected by HIV/AIDS emerges as a consistent theme: a Kenyan court upholds the rights of children with HIV to education, whereas in Hungary a youth with HIV is excluded from high school, seemingly without redress. HIV/AIDS legal education and advocacy are showing results: in the Caribbean, a regional project supports law reform in seven countries, while AIDS-law groups in Kenya and Zambia support reform through training and advocacy.

Contributors to International News in this issue are Otiende Amollo, Marie-Claude Chartier, Eszter Csernus, Malala Sakufiwa, and Wan Yanhai. We welcome information about new developments for future issues of the Review. Address correspondence to David Patterson, the editor of International News, at david.patterson@videotron.ca.

Caribbean: Regional support for HIV/AIDS law and policy reform

In this article, David Patterson describes the second regional training workshop on HIV/AIDS, law, ethics, and human rights, which took place in Georgetown, Guyana in November 2003; and a grant from the Global Fund to Fight HIV/AIDS, Tuberculosis and Malaria (the Global Fund) to the Pan Caribbean Partnership against HIV/AIDS (PANCAP). The grant focuses on human rights, prevention, and care and support.

CARICOM¹/PANCAP program on law, ethics, and human rights

In August 2003, the *Review* reported on the first Caribbean regional training workshop for HIV/AIDS-related law and policy reform.² That workshop was part of a larger CARICOM/PANCAP capacity-building program

on law, ethics, and human rights funded by the Canadian International Development Agency (CIDA) and the United States Agency for International Development. Components of the program include financial and technical support for national needs assessments for policy and law reform; national consultations on law and policy reform;

analysis on specific aspects of law reform; development of regional model policies, guidelines, and codes of practice; and training of legal-aid providers and organizations of people living with HIV/AIDS.

In November 2003, representatives of seven CARICOM member states (Antigua and Barbuda, Barbados, Dominica, Grenada,

Guyana, Saint Lucia, and St Vincent and the Grenadines) participated in the second regional training workshop for national assessments on HIV/AIDS, law, ethics, and human rights in Georgetown, Guyana. The participants included people from national AIDS programs and secretariats; NGOs working in HIV/AIDS; professionals with backgrounds in disciplines such as law, medicine, and psychosocial therapy; and people living with HIV/AIDS.

Resource persons from the Caribbean Regional Network of People Living with HIV/AIDS (Bermuda), the University of the West Indies, Norman Manley Law School (Jamaica), and Friends for Life (Trinidad and Tobago) also participated, as did representatives of CARICOM (including Youth Ambassadors), CIDA, and the Joint United Nations Programme on HIV/AIDS (UNAIDS). Prior to the workshop, several of the country teams identified a consultant to undertake the national assessment, and in some cases this person also attended the workshop with the country team. Jamaica, Belize, and Suriname have already completed national assessments and are now seeking community and political support for the reforms proposed. Trinidad and Tobago is also undertaking a national assessment on law and policy reform, with financial assistance from the United Nations Development Programme.

The idea for a national assessment of the need for HIV/AIDS-related law and policy reform came from the participants at the regional meeting in Tobago in June 2002 and is set out in the resulting Action Plan on Law, Ethics and Human Rights. The Action Plan proposes that “the

assessments should be time-limited, consider the broader social and institutional context, focus on priority areas for reform and provide concrete recommendations for reform consistent with international law.”³ Outcomes of the November 2003 workshop included draft country plans for the national assessments in the participating countries (including timelines, activities, key stakeholders, and a monitoring and evaluation framework) that will support funding proposals to PANCAP for assistance in undertaking the assessments. The national assessments are expected to be finished in mid-2004, after which a further process of national and regional advocacy is anticipated to generate community and governmental support for the reforms proposed in the assessments.

Technical support to PANCAP on law, ethics, and human rights is provided by the Canadian HIV/AIDS Legal Network through a Memorandum of Understanding with CARICOM. The Legal Network proposed a conceptual framework for the Action Plan, the workshops, and other activities that situate the program within the global and regional legal and policy context, including the International Guidelines on HIV/AIDS and Human Rights, the United Nations General Assembly Special Session (UNGASS) Declaration of Commitment on HIV/AIDS, the Nassau Declaration on Health, and the Pan Caribbean Partnership.

Central to the approaches adopted in these initiatives are the respect for the human rights of people living with and affected by HIV/AIDS and their involvement in all aspects of the response. The Legal Network’s role is one of process facilitation as well

as the provision of substantive advice on international law, best practice, and experiences from other regions. Assistance on project development, and monitoring and evaluation, is also provided. Consultants from the Caribbean region, including from the Guyana Human Rights Association (GHRA), were engaged to ensure that regional perspectives were reflected in the Action Plan and subsequent workshop design and facilitation.⁴ The CARICOM/PANCAP program on HIV/AIDS, law, ethics and human rights will be completed in March 2006.

Global Fund grant

In 2003, the Global Fund approved a five-year grant for US\$12.6 million to PANCAP to establish, consolidate, and coordinate regional support to Caribbean countries to reduce the impact of HIV/AIDS. The grant proposal is titled “Scaling Up the Regional Response to HIV/AIDS through the Pan Caribbean Partnership against HIV/AIDS” and has three elements: human rights, prevention, and care and support.⁵ The human rights component will build on the relevant components of the CARICOM/PANCAP program on HIV/AIDS, law, ethics and human rights, including through the wider dissemination of policies and best practices developed in the CARICOM/PANCAP program to PANCAP member states, people living with HIV/AIDS, and country-based decision-makers.

A key element of the human rights component of the Global Fund proposal focuses on stigma and discrimination. The proposal aims to reduce the levels of stigma and discrimination against people living with HIV/AIDS and their families

through the establishment of mechanisms to monitor human rights violations, to enable those whose rights have been violated to seek redress, and to access services to address individual or country-specific concerns. The proposal notes that “Countries will be encouraged to establish National Registries while the Pan Caribbean Partnership will establish a Regional Registry to keep track of incidences of violation reported and the way they are addressed at national levels.”⁶

The spectrum of potential HIV/AIDS-related human rights violations is clearly very broad, spanning the prevention–care continuum and implicating government and private-sector actors. It is unlikely to be restricted to people living with or affected by HIV/AIDS and their families, and would almost necessarily

include other groups facing HIV/AIDS-related discrimination in the Caribbean, such as prisoners, men who have sex with men, and sex workers.

This may be the first time that a regional body has been funded to document HIV/AIDS-related rights violations. There are exciting opportunities to link this initiative with existing regional and international human rights mechanisms. Another component of the proposal to reduce stigma and discrimination involves education, capacity building, and sensitization. Regional institutions such as the (proposed) Caribbean Court of Justice and the Caribbean Council of Legal Education will be required to integrate HIV/AIDS-related human rights issues into their respective programs. For further information, contact Alicia Sands,

PANCAP Information Officer, at asands@caricom.org.

¹ CARICOM is the Caribbean Community and Common Market, an intergovernmental organization headquartered in Georgetown, Guyana.

² Caribbean nations hold first training workshop on AIDS laws and policies. *Canadian HIV/AIDS Policy and Law Review* 2003; 8(2): 33-34. See also Caribbean countries address legal, ethical, human rights issues. *Canadian HIV/AIDS Policy and Law Review* 2002; 7(1): 44-45. This workshop report, the reports of the other workshops, the Action Plan on Law, Ethics and Human Rights, and other materials relevant to this program are available on the CARICOM website at www.caricom.org.

³ Action Plan on Law, Ethics and Human Rights. CARICOM/PANCAP, 2002. Available at www.caricom.org.

⁴ The GHRA is a human rights organization that includes HIV/AIDS-related human rights in its mandate, and addresses both human rights education and abuses of human rights relating to HIV/AIDS. For more information, contact Merle Mendonca (ghra_guy@networksgy.com).

⁵ Further details, including the full proposal, can be obtained from the Global Fund website at www.theglobalfund.org.

⁶ *Ibid* at 52.

China: People living with HIV complain about conduct of medical research

In January 2004, four people living with HIV/AIDS from Shuangmiao village, Henan Province, China, went public with complaints about the conduct of a medical experiment, raising questions about whether research subjects gave their informed consent to participate in the experiment. The complaints and questions were contained in a letter to the Ethics Review Panel of the Center for STD/AIDS Prevention and Control at the China Center for Disease Prevention and Control.¹

Shuangmiao has a population of over 3000 people, many of whom engaged in illegal and unsterile blood selling in the 1990s. According to the complaint, approximately 170 people have died of AIDS-related illness, and

about 400 others are living with HIV/AIDS. The complaint states that in February 2003, doctors and nurses from Beijing Ditan Hospital visited Shuangmiao and collected blood samples from 100 people without inform-

ing them of the purpose of the action. Not long afterward, seventeen people were summoned to Beijing Ditan Hospital for “treatment.” The complaint states, “At that time, we had no idea why the hospital chose us instead

of others; we also had no idea about the nature of the treatment we would be given.”

The complaint states that the hospital conducted further blood tests and other physical examinations, but that the patients did not receive the results. According to the complaint, in March 2003 the patients were asked to sign a patient's informed consent form that contained some words in English (none of the patients read or understand English), and were told that the treatment to be provided would assure them health and long life for many years. The complainants state that they did not receive a copy of the form at the time.

The patients were discharged from the hospital in May 2003, but returned to Beijing for regular blood tests and treatment until November 2003. The complainants state that throughout this period they did not receive results of examinations or

understand the significance of the tests or treatment. Compensation was provided for some expenses, including those incurred for travel to Beijing and for the period in hospital.

In January 2004, the hospital provided copies of the informed consent forms (after payment of a fee for photocopying the documents). The forms contained the following information:

- Objective of experiment: Assessment of safety and efficacy of Thymus Nuclear Protein injections for treating HIV-1 infected subjects.
- Sponsors & Principal Investigator: New York International Commerce Group (USA), Viral Genetics, Inc. (New York, USA), China Center for Disease Prevention and Control, Center for STD/AIDS Prevention and Control, Beijing Ditan Hospital.

- Study site: Beijing Ditan Hospital.

The complaint states that this was the only information the patients were given about the nature of the treatment they were to receive. The complainants are asking the Ethics Review Panel and the bodies with which it is associated to investigate these concerns and to help the complainants with their demand for financial compensation. The complainants are being assisted by the Beijing AIZHIXING Health Education Institute. For further information, contact Wan Yanhai (hiwan@public.bta.net.cn or hiwan@aizhi.org).

¹ The letter was circulated by Dr Wan Yanhai and was posted on the AIDSPOLICYLAW listserv on 16 January 2004. The listserv is operated by the Canadian HIV/AIDS Legal Network. Individuals can subscribe to the listserv via www.aidslaw.ca/mailling_list/description.htm.

Russian Federation: Penalties eased for possession of illegal drugs

In November 2003, after long deliberations, the Russian Parliament passed a bill amending the national Criminal Code to differentiate between the liability for possession of illegal drugs for drug users and for drug traffickers.¹ The reforms involved redefining the terms “large” and “extra-large” with respect to the quantities for possession and trafficking of illegal substances.² (There is no criminal liability for possession of less than a large amount.) On 16 December 2003, the new bill was enacted into law.

Under the old law, although the use of illegal substances was considered a misdemeanour, and there was no

criminal liability for drug use per se,³ drug users were often charged with the possession of illegal substances, a

crime punishable by up to three years in prison. If the intent was to sell the substances, the penalty was up to seven years in prison.⁴ The Criminal Code referred to the quantities of drugs necessary to charge someone with drug possession only as large and extra-large. The State Committee on Narcotic Drug Control defined what these terms meant. The amounts as defined by the State Committee were tiny: large quantities, for exam-

ple, included 0.001 grams of heroin or 0.5 grams of marijuana. Reportedly, around 90 percent of the people charged with illegal possession of heroin have less than one gram of the drug on them.⁵ Yet, under the law they faced lengthy prison sentences.⁶ People caught with extra-large quantities are usually given harsher penalties than those caught with large quantities.

The amendments introduced a new measurement, namely “an average dose for one-time consumption.”⁷ A quantity of illegal drug that exceeds this amount by 10 or more times is now considered a large quantity. If the amount exceeds the new measurement by 50 or more times, it is deemed to be an extra-large quantity. Possession of amounts less than 10 times the average dose for one-time consumption will no longer attract criminal liability.

Illegal production, provision, and sale of drugs, now punishable by a term of four to eight years in prison, is covered by a specific article in the Criminal Code, separate from possession and purchase, which is now punishable by a fine or up to three years in prison.⁸

The Russian government has been criticized for its repressive drug policies, which are believed to have exacerbated the spread and impact of HIV infection.⁹ Drug users in the Russian Federation are an extremely marginalized community, and are often discouraged from using social services because of the associated risks of criminal liability, stigma, and discrimination.¹⁰ Recently, more rational and humane policies toward drug users appear to be emerging. For more information, contact Anna Alexandrova (AnnaAlexandrova@aol.com).

¹ See Rossijskaya Gazeta. Federal Law “On Amending the Criminal Code of the Russian Federation N 162-FZ” (adopted December 08, 2003). Online in Russian: Rossijskaya Gazeta, www.rg.ru/2003/12/16/kodeks.html.

² Criminal Code of the Russian Federation (1996), article 226, paras 1, 2.

³ Code of Administrative Offences of the Russian Federation (2002), article 6.5.

⁴ Criminal Code of the Russian Federation (1996), article 226, paras 1, 2.

⁵ State Committee on Narcotic Drug Control. Table of Quantities (as per May 01, 1998) (adopted through Protocols N 53/9-9, December 17, 1996; N 54/10-96, December 25, 1996; N 2/56-97, April 30, 1997, N 3/57-97 June 04, 1997; N 1/63-98 March 18, 1998).

⁶ L. Levinson. The State Duma approved amendments to the Criminal Code. *Harm Reduction Bulletin AFEW*; 3(11). Online (Russian): www.afew.org

⁷ *Supra*, note 1.

⁸ *Ibid*, article 1 (228.1).

⁹ See, for example, K. Malinowska-Sempruch, J. Hoover, A. Alexandrova. *Unintended Consequences: Drug Policies Fuel HIV Epidemic in Russia and Ukraine*. New York: OSI, 2003. Online: www.soros.org/initiatives/ihrd/articles_publications/publications/unintendedconsequences_20030414.

¹⁰ K. Malinowska-Sempruch. The need for harm-reduction approaches in Eastern Europe and the former Soviet Union. *Canadian HIV/AIDS Policy & Law Review* 2002; 7(2/3): 84-88. Discrimination and human rights abuse in Russia. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 5(1): 22-27.

Kenya: AIDS-law sensitization results in schooling for orphans

In a landmark victory for children living with HIV/AIDS, in January 2004 the Kenyan High Court approved an agreement between the government and the Nyumbani Children’s Home whereby the Ministry of Education will admit HIV-positive children to government schools. Prior to the agreement, government practice was to refuse admission of children from the Nyumbani Children’s Home, Kenya’s oldest and largest AIDS orphanage, on grounds such as that the school was full to capacity or that the applicant had failed to produce a birth certificate. This was in spite of the fact that Kenya’s schools are already overcrowded and that births are often unregistered.

On 3 September 2003, the Chambers of Justice, a registered Nairobi-based human rights foundation, wrote to the Minister of Education seeking a directive to all school heads and education officials affirming the right to free primary education and the promulgation of procedures for admission to public schools that do not discriminate on the basis of HIV and other

grounds.¹ In arguing the case for the children of the Nyumbani Children's Home, the Chambers of Justice cited the Constitution of Kenya (which outlaws discriminatory practices), the African Charter on the Rights and Welfare of the Child, the United Nations Convention on the Rights of the Child, and the Universal Declaration of Human Rights.

In the absence of a timely reply to the letter, in December 2003 the children of the Nyumbani Children's Home filed suit against the government seeking an expedited hearing. On 7 January 2004, Justice Martha Koome heard the case, permitting over 30 of the children into her chambers, and directed the parties to find an amicable solution. On 9 January, the court approved an agree-

ment whereby the Director for City Education was to immediately commence the process of placing the Nyumbani children of school age in public schools within Nairobi, and undertake certain other measures.

This outcome is remarkable for a number of reasons, including: the explicit reference to international law; the mobilization and inclusion of the affected children in the judicial process; the expedited hearing; and the amicable settlement between the parties, which augers well for the implementation of the agreement.

The case occurred in the context of increasing community education on HIV/AIDS, law, and human rights in Kenya. The Kenya Ethical and Legal Issues Network on HIV/AIDS (KELIN) held sensitization work-

shops attended by representatives of the Nyumbani Children's Home. The Chief Counsel for the Chambers of Justice, which represented the children in the case, is a KELIN affiliate.

In 2002-2003, KELIN received technical and financial support from the Canadian HIV/AIDS Legal Network through a grant from the Canadian International Development Agency. The project was implemented in Kenya by the Kenyan AIDS NGOs Consortium. For further information, contact Otiende Amollo at otiende@rachieradvs.co.ke.

¹ For information on the Nyumbani Children's Home, see www.nyumbani.org/index.html. For the full text of the letter to the Minister of Education, see www.nyumbani.org/nyumbani_images/child_act.pdf.

Kenya: Labour law reform touches HIV/AIDS

April 2004 will see the culmination of a coordinated process of labour law reform in Kenya that will lead to revised and updated laws, including some laws relating to HIV/AIDS. The new laws will also foster strengthened social dialogue in a legal framework consistent with the International Labour Organization (ILO) standards ratified by Kenya.¹ The process is supported by the ILO, with funding from the United Nations Development Programme and the US Department of Labor.

A tripartite Task Force (government, employers, workers) was appointed in late May 2001 and set about establishing a detailed work plan, with activities and outputs planned through to April 2004, when its Final Report and

the draft legislation are scheduled to be submitted to the Minister of Labour and Human Resource Development. Many nationwide consultations have been sponsored by the project. In the first round of media calls for public

comment, approximately 40 institutions, NGOs, and individuals sent in their views on what the new labour laws should contain.

Throughout the revision process, there has been great interest in includ-

ing provisions that will address HIV/AIDS in the world of work. The Task Force was conscious of the need to reflect Kenya's National Gender Policy, and to respond to the needs of workers and employers who are affected by the AIDS epidemic. For example, the draft Employment Act prohibits discrimination, harassment, and dismissal on the basis of HIV status. These sections, when adopted, will reinforce the protection afforded by the HIV/AIDS Prevention and Control Bill, 2003.² That Bill, adopted in September 2003, provided for HIV/AIDS education (with particular emphasis on schools, workplaces, health-care services, and communities), confidentiality of HIV/AIDS records and information, and access to health-care services. It outlawed discriminatory acts and practices against people living with HIV/AIDS, and prohibited compulsory HIV testing as a precondition for employment, marriage, education, entry into (or travel out of) the country, provision of health care, insurance coverage, or any other service.

For more information, contact Marie-Claude Chartier or Jane Hodges at the International Labour Organization (chartier@ilo.org; hodges@ilo.org).

¹ Kenya has ratified 49 ILO conventions. A complete list of countries and conventions ratified is available at www.ilo.org/ilolex/english/newcountryframeE.htm. Although there is no AIDS-specific ILO convention, a large number of these conventions are relevant to HIV/AIDS in that they deal with protection against discrimination, occupational health and safety issues, and social protection; and they cover specific groups of workers (eg, nursing personnel, migrant workers, part-time workers).

² 23 September 2003, Kenya Gazette Supplement No 76 (Bill No 22).

African ILO meeting endorses efforts by employers' and workers' organizations to fight HIV/AIDS

In December 2003, the Tenth African International Labour Organization (ILO) Regional Meeting in Addis Ababa, Ethiopia adopted a resolution on HIV/AIDS calling on African governments to support the efforts of employers and workers to combat HIV/AIDS – by providing an enabling legal and policy framework for workplace action, by providing measures to oppose stigma and discrimination, and by strengthening national AIDS plans through the inclusion of a strategy for the world of work.¹ The resolution also called on workers' and employers' organizations to increase their joint efforts to reduce the spread and impact of HIV/AIDS. Finally, the resolution called on the ILO to give greater priority to its efforts to combat the pandemic in Africa.

The Addis Ababa resolution follows the UN Global Compact Policy Dialogue on HIV/AIDS hosted by the ILO in May 2003. During this event, the Secretaries General of the International Organization of Employers (IOE) and the International Confederation of Free Trade Unions (ICFTU) issued a historic joint statement committing their organizations and members to collaborative action on HIV/AIDS at all levels, especially in the workplace. The IOE represents 137 national employers' organizations from 133 countries; the ICFTU has 231 affiliated national trade union centres in 150 countries, representing 158 million members.

In order to give effect to the joint statement and the resolution on HIV/AIDS, IOE/ICFTU national

action plans on HIV/AIDS in the workplace will be launched in eight African countries: Ivory Coast, Ghana, Kenya, Malawi, Mali, Uganda, Tanzania, and Zambia. The process will start in Africa, but the experience gathered in the continent will be critical in helping to develop interventions in other regions where the epidemic is progressing rapidly – such as Eastern Europe, India, the Caribbean, and China. For more information, contact Susan Leather or Marie-Claude Chartier at the International Labour Organization (leather@ilo.org; chartier@ilo.org).

¹ Fighting HIV/AIDS Together – A Programme for Future Engagement. Available at www.ilo.org/aids. The ILO website also contains a collection of national laws and policies dealing, entirely or in part, with HIV/AIDS and the world of work.

Africa: Regional workshop held on HIV/AIDS and the right to health

In October 2003, the AIDS and Rights Alliance of Southern African (ARASA) and the Zambia AIDS Law Research and Advocacy Network (ZARAN) held a regional workshop on HIV/AIDS and the Right to Health: Challenges and Opportunities, at Kafue Gorge, Zambia.

Participants came from Zambia, Zimbabwe, and Malawi. One participant commented that the meeting recalled the coming together of Rhodesia and Nyasaland – the former colonial names for these countries. Resource persons were drawn from Zambia, the AIDS Law Project of South Africa, and the AIDS Legal Unit of Namibia. The workshop explored the implementation of the right to health in the context of HIV/AIDS, as well as challenges to the enjoyment of that right. Specifically, the workshop introduced participants to relevant international and regional human rights standards and guidelines, and concepts of intellectual property law relating to access to essential medicines.

Participants also discussed the role of law and policy in fulfilling the right to health; ways to achieve regional action on the right to health; access to medicines; anti-discrimination; and

the formation of strategic alliances to improve government accountability and health delivery. Two common challenges were identified: first, a lack of a holistic approach to treatment (for example, one that includes good nutrition) – in most instances, the approach is narrow and concentrates on access to drugs alone; and second, the absence of adequate constitutional protections for the right to health in the three countries.

The participants proposed actions, including popularizing the concept of the right to health – for example, through a protocol to the treaty that established the Southern African Development Community – and advocacy for domestic law reform to advance the right to health. Recognizing that regional approaches can support national reforms, the participants formulated several recommendations for ARASA, including a study of regulatory frameworks

in the region to evaluate the extent to which they guarantee the right to health, and a campaign to popularize the right to health on regional basis – specifically, a regional day of action on the right to health.

In 2002-2003, ZARAN received financial support from the Canadian International Development Agency through a joint project with the Canadian HIV/AIDS Legal Network and the International HIV/AIDS Alliance.¹ ARASA is an alliance of organizations in Southern Africa working on HIV/AIDS and human rights.² For more information, contact Malala Sakufiwa at ZARAN (malalam2000@yahoo.com) or Collette Campher at ARASA (arasa@lac.org.na).

¹ For further information on ZARAN, see the organization's website at www.zaran.org.

² See AIDS and Rights Alliance for Southern Africa. *Canadian HIV/AIDS Policy & Law Review* 2003; 8(1): 33.

Hungary: Unjustified discrimination confirms need for greater awareness

When young G's parents learned that their son had passed his entrance exam for the technical school he

wanted to go to, they asked to see the principal. No law or regulation obliged them to do so, but they pre-

ferred to inform the institution that their son was seropositive. Their choice was based on their desire to

avoid any future speculation, and they also considered it preferable to let those who would be in daily charge of their son know about his condition. Unfortunately, the principal reacted by denying their son admission to the school.

The educational rights commissioner, who has a merely advisory role in Hungary, attempted to reconcile the parties, but without success; the report in which he stated that the refusal to allow G to register contravened the public education law and the Constitution was not acted upon. The family still had the option of instituting administrative or legal proceedings. They could have applied to a court to rule that their rights were infringed and claim damages, but, considering that the publicity the matter would receive would deprive them of the only real protection they had – their anonymity – they preferred not to take the judicial route.

Instead, they asked the school managers – the Budapest municipal

council – to look into the matter and to sanction the principal. Although the hearing was initially favourable to the complainants, the commission involved concluded that there were legal uncertainties in the case and that the principal lacked sufficient information at the time he had to decide such a delicate issue. Given the uncertainties, the commission said, the principal could not be blamed for having chosen to protect the interests and the health of his other students.

The commission also stated that it was incumbent on the mayor of Budapest to ensure that the institutions managed by the city were in possession of the necessary information, and it made the mayor responsible for providing schools with an adequate guide. Such a guide is currently being developed, and the comments of the educational rights commissioner, as well as the legal opinion of the Hungarian Civil Liberties Union (HCLU), which has

supported the complainants from the outset, will be taken into account when it is drafted.

Through its initiatives, articles, and interviews the HCLU is trying to make the general public and local and government authorities understand that regular information campaigns are necessary in order to make the legal measures that currently exist effective (but that will remain ineffective if those who are charged with applying them are not convinced of their legitimacy). In the meantime, young G is taking night courses in another institution and wants to forget this whole incident as quickly as possible.

For more information on HIV/AIDS and human rights in Hungary (in English and Hungarian), visit the website www.tasz.hu or contact Eszter Csernus at the HCLU (csernuse@tasz.hu). See also *HIV/AIDS and Human Rights in Hungary. Budapest, 2004* (available from the HCLU).

Eastern Europe and Central Asia: report identifies human rights gaps

Criminalization and stigmatization of the high-risk behaviours that promote the spread of HIV are fuelling the HIV/AIDS epidemic in Eastern Europe and Central Asia and placing millions of people at risk. This is one of the findings of a report from the United Nations Development Programme released in February 2004.¹ The report, which is the first comprehensive profile of the epidemic in the 28 countries of the region, includes a significant focus on human rights issues.

The report says that 20 percent of the countries in the region have not passed anti-discrimination legislation

or laws to protect vulnerable groups. It adds that even where such laws have been passed, “the gap between

theory and practice is not closing fast enough to fully protect the human rights of the members of marginalised

groups that are most at risk.”² The report says that

Laws intended to protect the rights and health of people living with (or most at risk of contracting) HIV are often not enforced. In some cases, this is because countries are financially unable to comply with their own legislation on providing effective health care services to people living with HIV/AIDS. In other cases, however, the implementation of effective HIV-related legislation and policies is hampered by widespread disinterest, intolerance, and discrimination.³

The report states that “the human rights of sex workers, prisoners and other marginalised groups are routinely violated in many countries.”⁴ It says that many countries in the region have responded to increased drug use by implementing punitive anti-drug measures, and that this approach has

greatly increased the number of injecting drug users in prison – where drug use and needle-sharing are ram-

panant, condoms are generally unavailable, and treatment and other services for drug users are lacking.⁵

The report adds that the right to protect one’s health is severely compromised by laws restricting or forbidding the supply of harm-reduction services.

The report says that

respecting the human rights, and responding to the concerns, of people living with HIV/AIDS and others in marginalised, high-risk communities must be vital elements of any effective response to the epidemic⁶

and that at-risk individuals and civil society organizations must be involved in the planning and implementation of programs to fight the epidemic.

The report concludes that

the implementation of human rights guarantees requires a rebalancing of social priorities, away from intolerance and law enforcement approaches that exclude injecting drug users, sex workers, ethnic minorities and homosexuals

from the social mainstream. Injecting drug use and sex work must instead be viewed through a public health lens, in order to facilitate the deployment of harm reduction projects.⁷

Finally, the report recommends that obstacles to greater engagement in HIV/AIDS programming by civil society groups be identified and removed, and that multisectoral policy responses must be reinforced by commitment from political and other leaders to ensure that the rights of marginalized groups are respected by all state agencies.

¹ United Nations Development Programme. *Reversing the epidemic: facts and policy options*. Bratislava, February 2004. Available at www.undp.sk/hiv/?english.

² *Ibid* at 49.

³ *Ibid* at 56.

⁴ *Ibid* at 52.

⁵ *Ibid* at 55.

⁶ *Ibid* at 50.

⁷ *Ibid* at 61.

HIV/AIDS IN PRISONS

This section of the Review addresses issues related to HIV/AIDS in prisons. The articles have been compiled by Ralf Jürgens, Executive Director of the Canadian HIV/AIDS Legal Network. Ralf can be reached at ralfj@aidslaw.ca.

We begin with a story about the Dublin Declaration on HIV/AIDS in Prisons. The Declaration, which was launched in February 2004, should be used by prison systems worldwide as a framework for effective action on HIV/AIDS in prisons, and by community advocates as an additional tool to hold governments accountable for their failure to act. Because of its importance, we reproduce the full text of the Declaration. We then summarize the most recent review of prison needle exchange programs, which again concludes that such programs have been proven effective and should be introduced in other prison systems. This is a recommendation made also by Portugal's Justice Ombudsman, who went even further and suggested that safe injection sites should be established in Portuguese prisons. Finally, we report on a few additional recent developments in prisons in Canada and elsewhere, and on a new web resource that provides links to some of the best resources about HIV/AIDS and prison issues on the web.

Dublin Declaration on HIV/AIDS in prisons launched

On 23 February 2004, the Dublin Declaration on HIV/AIDS in Prisons in Europe and Central Asia¹ was launched. The Declaration focuses on prisons in Europe and Central Asia, but it is also relevant for prisons in other countries, including Canada, which are still far from having adopted a comprehensive approach, based on public health and human rights principles, to HIV/AIDS and hepatitis C in prisons.

The Declaration was released in Dublin by a coalition of community-based organizations, including the Irish Penal Reform Trust and the Canadian HIV/AIDS Legal Network, during a conference entitled *Breaking the Barriers – Partnership to fight HIV/AIDS in Europe and Central Asia*. This conference, attended by representatives of states and governments from Europe and Central Asia, was aimed at increasing the commitment to fight HIV/AIDS in Europe and Central Asia.² By the time it was launched, over 80 organizations and individuals from over 23 countries had already signed on to the Declaration.

The Declaration on HIV/AIDS in Prisons points out that HIV/AIDS is a serious problem for prison populations across Europe and Central Asia (and in other parts of the world), and that in most countries, rates of HIV infection are many times higher amongst prisoners than amongst the population outside prisons. This situation is often exacerbated by high rates of hepatitis C and/or multi-drug resistant tuberculosis. In most cases, high rates of HIV infection are linked to the sharing of injecting equipment

both inside and outside prison walls and to unprotected sexual encounters in prison. In a majority of countries, adequate preventive measures have not been introduced in prisons, although they have been successfully introduced in prison systems in some countries and shown to be effective. As a result, people in prison are placed at increased risk of HIV infection, and prisoners living with HIV/AIDS are placed at increased risk of health decline, of co-infection with hepatitis C and/or tuberculosis, and of early death.

According to the Declaration, the failure to implement comprehensive programs that are known to reduce the risk of HIV transmission in prisons and to promote the health of prisoners living with HIV/AIDS is

often due to lack of political will or to policies that prioritize zero-tolerance to drug use over zero-tolerance to HIV/AIDS. In some cases, it is the result of a lack of state resources and technology to meet the overwhelming need. In some cases, it is both.

The Declaration urges governments to act, and provides a framework for mounting an effective response to

HIV/AIDS in prisons, based upon recognized international best practice, scientific evidence, and respect for the human rights of people in prison.

The Dublin Declaration on HIV/AIDS in Prisons, reproduced below, should be used by prison systems worldwide as a framework for effective action on HIV/AIDS in prisons; and by community advocates as an additional tool to hold governments accountable for their failure to act.

– Ralf Jürgens

Ralf Jürgens was one of three NGO representatives at the Policy Dialogue. He can be reached at ralfj@aidslaw.ca.

¹ Dublin Declaration on HIV/AIDS in Prisons in Europe and Central Asia. Prepared by R Lines, R Jürgens, H Stöver; G Kaliakbarova, D Latcevschi, J Nelles, M MacDonald, M Curtis. Available at www.aidslaw.ca/Maincontent/issues/prisons.htm.

² Representatives of these states and governments adopted another “Dublin Declaration,” the Draft Dublin Declaration on Partnership to fight HIV/AIDS in Europe and Central Asia (available at www.dochas.ie/Working_Groups/HIV-AIDS/draft_dublin_declaration_on_hiv.htm). This Declaration mentions prisoners as one of the “most vulnerable groups to high and immediate risk from HIV/AIDS infection,” but fails to set specific targets for prevention or care, treatment, and support for prisoners. It does “confirm that the respect, protection and promotion of human rights is fundamental to preventing transmission of HIV, reducing vulnerability to infection and dealing with the impact of HIV/AIDS.”

Dublin Declaration on HIV/AIDS in Prisons in Europe and Central Asia

Prison Health is Public Health

Dublin, Ireland

February 23, 2004

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HIV/AIDS in Europe and Central Asia*

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Preamble

HIV/AIDS is a serious problem for prison populations across Europe and Central Asia.

In most countries, rates of HIV infection are many times higher amongst prisoners than amongst the population outside prisons.[†] This situation is often exacerbated by high rates of Hepatitis C and/or (multi-drug resistant) Tuberculosis in many countries. In most cases, high rates of HIV infection are linked to the sharing of injecting equipment both inside and outside prison walls and to unprotected sexual encounters in prison. In a majority of countries, adequate preventive measures have not been introduced in prisons, although they have been successfully introduced in other prison systems and shown to be effective. As a result, people in prison are placed at increased risk of HIV infection, and prisoners living with HIV/AIDS are placed at increased risk of health decline, of co-infection with Hepatitis C and/or TB, and of early death.

The failure to implement comprehensive programmes that are known to reduce the risk of HIV transmission in prisons and to promote the health of prisoners living with HIV/AIDS is often due to lack of political will or to policies that prioritize zero-tolerance to drug use over zero-tolerance to HIV/AIDS. In some cases, it is the result of a lack of state resources and technology to meet the overwhelming need. In some cases it is both.

This public health crisis requires urgent attention and action from all governments.

Under national and international law, governments have a moral and ethical obligation to prevent the spread of HIV/AIDS in prisons, and to provide proper and compassionate care, treatment, and support for those infected. What needs to be done is clear: policies and programmes that effectively reduce the spread of HIV in prisons and provide care, treatment and support for prisoners living with HIV/AIDS already exist in several countries and should be replicated elsewhere.

People in prison have the same right to health as people outside, and the lives and health of people in prison are connected to those of people outside prison in many ways. If we protect them, we also protect our broader communities. Protecting prisoners will also protect prison staff, who also have a right to be protected against HIV/AIDS, Hepatitis C, and TB in prisons, and whose needs are entirely compatible to those of the prisoners in this respect.

As the representatives of 55 governments from Europe and Central Asia gather in Dublin this week to discuss “Breaking the Barriers” in the fight against HIV/AIDS, we call upon them to begin by breaking down the barriers over which they have total control – the barriers that have thus far prevented comprehensive HIV/AIDS services from being implemented in prisons.

Purpose

This Declaration provides a framework for mounting an effective response to HIV/AIDS in the prisons of Europe and Central Asia. The Principles and Articles outlined herein are based upon recognized international best practice, scientific evidence, and the fundamental human rights of people in prison and the obligations of States to fulfil those rights.

Statement of Fundamental Principles

Principle 1: People in prison are part of our communities.

People in prison are fathers and mothers, brothers and sisters, sons and daughters, grandfathers and grandmothers, husbands and wives, lovers, partners and friends. The fact that they are incarcerated for a period of time does not change this fact. Prisoners come from our communities and the vast majority return to our communities.

Principle 2: People in prison have a right to health.

This right is guaranteed in international law, as well as in international rules, guidelines, and covenants including the *Universal Declaration of Human Rights*, the *International Covenant on Economic, Social and Cultural Rights* (Article 12), the *International Covenant on Civil and Political Rights* (Article 10.1), the United Nation’s *Basic Principles for the Treatment of Prisoners* (Principles 5 and 9), and the Council of Europe’s *Committee of Ministers to Member States Concerning the Ethical and Organisational Aspects of Health Care in Prison* (Recommendation 10). This includes the right to medical treatment and to preventive measures, and to standards of health care equivalent to that available in the community. States are obligated to uphold this principle. Those that do not are in violation of both international law and international guidelines on the treatment of prisoners.

Principle 3: Good prison health is good public health.

The vast majority of people sent to prison eventually return to the community. Therefore any diseases contracted in prison, or any illnesses made worse by the conditions of confinement, become issues of public health when people are released. Governments cannot ignore prison health issues, as they are fundamentally a component of public health. Reducing the transmission of HIV and Hepatitis C in prisons is an important element in reducing the spread of these diseases in the broader population. Implementing effective TB treatment programmes in prisons will prevent the spread of (multi-drug resistant) Tuberculosis inside and outside prison.

Principle 4: Protecting the health of prisoners, and reducing the transmission of disease in prisons, also protects the health of prison staff.

Prison staff benefits from enhancing the health status of prisoners, and reducing the incidence of disease in penal institutions. Therefore, improving health care and prevention programmes for prisoners is an integral part of enhancing workplace health and safety for prison staff.

Principle 5: Sex and injecting drug use occur in prison, and in many prisons are widespread.

Experience in many countries in Europe and Central Asia (as in other parts of the world) has shown that sexual activity and injecting drug use occur in prisons, and are often widespread. Governments must publicly recognise this situation and act to implement appropriate health interventions. Denial of this reality by governments inhibits the fight against HIV/AIDS in prisons.

Principle 6: Harm reduction, rather than zero-tolerance, must be the pragmatic policy basis for fighting HIV/AIDS in prisons and in providing HIV/AIDS care.

International evidence has shown that HIV transmission can occur in prison, sometimes with alarming speed. Zero-tolerance policies towards drug use can create barriers to the fight against HIV/AIDS in prisons. The criminalization of drug use has ensured that drug users comprise a disproportionate part of prison populations. Many drug users do not cease using drugs simply because they are imprisoned. Many prisoners continue to inject on a regular or occasional basis during their incarceration. Zero-tolerance approaches towards drug use that ignore

this reality result in prison policies that increase the likelihood that these injecting practices will be unsafe, and heighten the risk of HIV transmission. Therefore, in order to effectively fight HIV/AIDS in prisons, prison and health policy must be based on the philosophy of harm reduction.*

Principle 7: HIV/AIDS in prisons is a major problem in many countries, and States must act collectively and cooperatively in the fight against the epidemic.

HIV/AIDS is an international problem that demands international solutions. Preventing HIV transmission in prisons and providing treatment for prisoners living with HIV/AIDS can be costly. In this fight, wealthier countries have a moral obligation to assist countries that are less wealthy.

Principle 8: Action to fight Hepatitis C in prisons is as crucial as is action to fight HIV/AIDS, and must be integrated into all initiatives addressing HIV/AIDS prevention and treatment.

Hepatitis C is an infection driven largely by unsafe injecting practices. In the prisons of many countries, rates of Hepatitis C infection are also many times higher than in the outside community, and many prisoners living with HIV/AIDS are also co-infected with Hepatitis C. Therefore, the fight against Hepatitis C in prisons is integrally linked to the fight against HIV/AIDS. The rights and principles outlined in this Declaration apply equally to the issue of Hepatitis C, and government strategies to combat the transmission of HIV and to care for those living with the illness must be integrated with those of Hepatitis C.

Framework for Action

Article 1: Prisoners have a right to protect themselves against HIV infection. Prisoners living with HIV/AIDS have a right to protect themselves from re-infection and/or co-infection with Hepatitis C and/or TB.

Therefore, States have a responsibility to

- Ensure that HIV prevention measures available in the outside community are also available in prisons. This includes providing prisoners with free access to HIV prevention and harm reduction measures including,

but not limited to, sterile syringes and injecting paraphernalia; condoms and other safer sex materials; bleach and disinfectants; safer tattooing equipment.

- Provide free access to methadone and other substitution treatments to prisoners in those countries where these treatments are provided in the community. This must include both the ability of people who are already on such a treatment to continue it when incarcerated, and the ability to initiate substitution programmes during incarceration. Countries that have not legalized or implemented substitution treatments should do so.
- Provide access to harm reduction measures in a confidential and non-discriminatory fashion.
- Provide accurate and easily understood information on the proper use of harm reduction measures using an effective means of delivery.
- Offer effective and timely treatment of Tuberculosis inside prison walls and ensure proper follow up when released in society.

Article 2: Prisoners living with HIV/AIDS have a right to maintain and promote their health.

Therefore, States have a responsibility to

- Provide free access to HIV/AIDS treatment and care that is equivalent to that available to people outside prison. This should include antiretroviral treatment, proper diet, health promotion options, and pain management medications.
- Provide prisoners with the same access to non-approved, investigational, and non-conventional and alternative therapies that people outside prison have.
- Provide quality gynecological and obstetrical care for HIV positive pregnant women in prison, including antiretroviral therapy on a continuous basis, and prophylaxis for the infant during and post-delivery to ensure that vertical transmission of the infection is interrupted.
- Provide sufficient levels of qualified medical personnel in prisons.
- Include treatment of STIs as a key component of a comprehensive HIV care.
- Improve conditions of confinement (overcrowding, poor prison conditions, poor sanitation, poor lighting and ventilation) that can negatively affect people with weakened immune systems.
- Provide access for non-governmental organizations

and other external health professionals to assist in the provision of care, treatment, and support services.

Article 3: Prisoners have a right to keep their HIV status confidential.

Therefore, States have a responsibility to

- Ensure that the security and confidentiality of prisoners' medical information is guaranteed.
- Ensure that prisoners are not housed, categorized, or treated in such a fashion as to disclose their HIV status, and that prison records are not marked or labelled in such a manner as to disclose HIV status.

Article 4: Prisoners have a right to informed consent in accessing HIV treatments and therapies, including the right to refuse treatment.

Therefore, States have a responsibility to

- Prohibit mandatory treatment of prisoners living with HIV/AIDS.
- Ensure that prisoners are provided with information on HIV treatments and therapies sufficient to enable them to make an informed choice about their treatment options.

Article 5: Prisoners have a right to access voluntary, confidential HIV testing, with pre- and post-test counselling. Prisoners have a right to informed consent before being tested for HIV infection, including the right to refuse testing.

Therefore, States have a responsibility to

- Prohibit mandatory HIV testing of prisoners.
- Provide access to voluntary, confidential HIV testing for prisoners.
- Ensure that proper pre- and post-test counselling is a mandatory component of HIV testing protocols and practice.
- Provide access to anonymous HIV testing to prisoners in countries where such testing is available in the community.

Article 6: Prisoners living with HIV/AIDS have a right to live free from stigma, discrimination, and violence.

Therefore, States have a responsibility to

- Ensure that prisoners living with HIV/AIDS are not involuntarily segregated or isolated from the general prison population because of their HIV status.
- Ensure that prisoners living with HIV/AIDS are not prohibited from participation in prison programming, work, or recreational activities because of their HIV status.
- Provide education on HIV/AIDS for all prisoners and prison staff.
- Combat AIDS-phobia among prisoners and prison staff.
- Provide regular training on communicable diseases and drug use for all prison staff, and to update this training on a regular basis.

Article 7: Prisoners have a right to accurate, non-judgemental, and accessible education on HIV/AIDS.

Therefore, States have a responsibility to

- Provide free access to such educational information in various formats on an ongoing basis.
- Address HIV prevention as one component within a comprehensive programme of STI prevention.
- Provide access for non-governmental organizations and other external health professionals to assist in the provision of educational interventions.
- Provide support for peer education initiatives by prisoners themselves.

Article 8: Prison populations have a right to have their diversity acknowledged and respected in the design and provision of HIV/AIDS services.

Therefore, States have a responsibility to

- Provide HIV/AIDS interventions and services that address and respect differences in gender, age, race, ethnicity, language, sexual orientation, and gender identity.

Article 9: Prisoners, prison staff, and non-governmental organizations should be consulted in the design and implementation of prison HIV/AIDS programmes.

Therefore, States have a responsibility to

- Create mechanisms that allow for meaningful input from prisoners, prison staff, and non-governmental

organizations in the content, design, and delivery of HIV/AIDS programmes.

- Encourage and support peer-led educational and support interventions by prisoners themselves.
- Ensure the sustainability of short-term NGO interventions by embedding them within prison programming.

Article 10: Prisoners living with HIV/AIDS have a right to a continuity of post-release healthcare services.

Therefore, States have a responsibility to

- Create systems of referral between prisons and community healthcare, social services, substitution treatment, and harm reduction services.
- Ensure that community health and social services receive sufficient resources and other supports to enable them to provide post-release care for ex-prisoners.

Article 11: Wealthier states have an obligation to assist and support less-wealthy states in providing HIV prevention and treatment options to prisoners.

Therefore, wealthier States have a responsibility to

- Provide affordable access to HIV treatments and therapies, harm reduction measures, and technical expertise to countries with fewer resources and medical/pharmaceutical infrastructure. This must include allowing for the development of generic HIV drugs.

† Studies in various countries in Western Europe, Eastern Europe and Central Asia have found rates of HIV infection between 0-17% among prisoners.

* Harm reduction is a set of practical strategies that reduce negative consequences of drug use, incorporating a spectrum of strategies from safer use, to managed use to abstinence. This includes discouraging the sharing of contaminated injecting equipment by providing sterile injecting equipment and disinfectant materials to users, and providing a range of drug dependence treatment including substitution treatment. Harm reduction accepts, for better and for worse, that licit and illicit drug use is part of our world and chooses to work to minimize its harmful effects rather than simply ignore or condemn them. Rather, harm reduction understands drug use as a complex, multi-faceted phenomenon that encompasses a continuum of behaviours from severe abuse to total abstinence, and acknowledges that some ways of using drugs are clearly safer than others. Harm reduction strategies meet drug users "where they're at," addressing conditions of use along with the use itself, and calls for the non-judgmental, non-coercive provision of services and resources to people who use drugs and the communities in which they live in order to assist them in reducing attendant harm. [Definition adapted from the Harm Reduction Coalition, www.harmreduction.org]

Another review of prison-based needle exchange programs published

In volume 8, issue 1 of the *Review*, we reported on the publication of a review of prison-based syringe-exchange programs (PSEPs) that concluded that such programs “are feasible and do provide benefit in the reduction of risk behaviour and the transmission of blood-borne infection without any unintended negative consequences.”¹ Another, more comprehensive review was recently published,² confirming once again that PSEPs have been successful where they have been introduced.

The review presents the results of PSEPs based on 10 years of experience in Switzerland, Germany, Spain, and Moldova. At the time the review was written (December 2002), PSEPs had been introduced in 46 prisons in these countries, and 43 of the programs were still operating. In the prisons in Germany in which programs were closed in 2002 and 2003, this was not the result of any problems with the programs, but rather of political interference by newly elected centre-right governments.³

In 11 prisons, PSEPs were evaluated to assess feasibility and efficacy. Results of these evaluations did not support the arguments most commonly used against the establishment of PSEPs: that they would lead to threatening scenarios against personnel and other prisoners; lead to increased consumption of drugs; lead to an increased use of injectable drugs for those who used drugs in other ways; and encourage non-users to start injecting drugs. In fact, evaluations showed that syringe distribution was not followed by an increase in drug use or injection drug use. Syringes were not misused, and disposal of used syringes was uncompli-

cated. Sharing of syringes among drug users decreased. The authors of the review concluded that, “Based on these experiences, ... harm reduction measures, including syringe exchange, were not only feasible but efficient [in prison].”⁴

Nevertheless, the resistance of prison staff, politicians, and trade unions against PSEPs and other harm-reduction measures has continued to block their introduction in most countries. The authors write:

Syringe exchange schemes are still a hot political issue because they are supposed to symbolise the failure of keeping prisons “drug free.” [PSEPs] are still subject to political decisions and strategies. In Hamburg, Germany, for instance, all three projects were running successfully. The middle-right wing coalition, which had been elected in September 2001, abolished harm reduction measures and declared a drug-free prison as main target, to which all other measures have to be subordinated.⁵

But there is hope. A Spanish government decree that all prisons in the country are required to provide drug users with sterile injection equipment “may lead to a breakthrough of this

harm reduction measure in the future.”⁶ Recently, a growing number of countries, particularly in Eastern Europe, have introduced PSEPs. The total number of such programs is now estimated to exceed 100. Another review of these programs, which will provide a lot more information about them, will be published later in 2004.⁷

—Ralf Jürgens

¹ R Jürgens. Review of prison-based needle exchange programs published. *Canadian HIV/AIDS Policy & Law Review* 2003; 8(1): 55, with reference to K Dolan, S Rutter, AD Wodak. Prison-based syringe exchange programmes: a review of international research and development. *Addiction* 2003; 98: 153-158.

² H Stöver, J Nelles. Ten years of experience with needle and syringe exchange programmes in European prisons. *International Journal of Drug Policy* 2003; 14: 437-444.

³ For more details, see R Lines, R Jürgens, H Stöver, D Laticeschi, J Nelles. *Prison Needle Exchange: A Review of International Evidence and Experience*. Montréal: Canadian HIV/AIDS Legal Network (forthcoming; this report will become available at www.aidslaw.ca/Maincontent/issues/prisons.htm).

⁴ *Supra*, note 2 at 437.

⁵ *Ibid* at 442.

⁶ *Ibid* at 437.

⁷ *Supra*, note 3.

Canadian Human Rights Commission recommends prison needle exchange programs

In a report released on 28 January 2004, the Canadian Human Rights Commission recommended that the Correctional Service of Canada (CSC) implement a pilot needle exchange program in three or more correctional facilities, at least one of them a women's facility, by June 2004.¹

The report highlighted that HIV infection rates among women offenders are even higher than among male offenders, and that drug use and needle sharing are prevalent in prisons. It provided the following human rights analysis of CSC's failure to date to pilot needle exchange programs in federal prisons:

The high rate of drug use and HIV infection means that the lack of clean needles in prisons has an adverse impact on drug dependent inmates. Although sharing dirty needles poses risks for any inmate, the impact on women is greater because of the higher rate of drug use and HIV infection in this population. This impact may be particularly acute for federally sentenced Aboriginal women.

The human rights analysis starts from the fact that Parliament chose to include protection against discrimination on the basis of substance dependence in the *Canadian Human Rights Act*. Harm reduction measures are a benefit available to drug dependent persons outside prison. Denying harm reduction measures that are consistent with accepted community health standards to incarcerated drug dependent inmates exposes them to increased risk.

Discouraging drug use among inmates and enhancing institutional safety are laudable goals. These goals are undeniably legitimate and important in the correctional context given

the relationship between drug use and criminal activity. However, it is not clear that limiting the availability of harm reduction measures that are consistent with community health standards discourages drug use among drug dependent inmates or contributes to the safety of staff, inmates or the public.

Drug use in federal prisons continues to be widespread and that means that inmates use dirty needles. Studies have shown that the availability of needle exchange does not lead to an increase in drug use, nor does a lack of clean needles discourage drug use in prison, even first-time use.

Zero tolerance is currently unenforceable, and this fact is being tacitly acknowledged by the Correctional Service when it provides bleach for needle cleaning or creates drug-free ranges and houses.

It is unlikely that Correctional Service's current practice of limiting the availability of harm reduction measures can be justified on the basis of undue hardship arising from safety, increasing as it does the risk of infection to inmates and, probably, to the public as well....

A consideration of risk to public safety is currently absent from the Service's policy of limiting the availability of harm reduction measures. Best practices for human rights compliance require a thorough consideration of all risks to safety arising from

the introduction of additional harm reduction measures. This is necessary in order to ensure a complete and balanced analysis of undue hardship.

Although some correctional staff working in institutions have opposed needle exchange citing a concern of increased risk of needle sticks, studies of needle exchange programs in prisons elsewhere do not support this apprehension. It is not clear that a needle exchange would increase risk and, in fact, pilot projects elsewhere show that a clean needle exchange program may make it easier to control the number of needles in an institution.²

The Commission concluded:

Given the benefits of harm reduction measures for drug dependent inmates, it is time to explore the introduction of additional measures that are consistent with community health standards. We agree with the recent report of the Office of the Correctional Investigator that there is a need for the implementation of further harm reduction measures that include needle exchange.³

The Commission therefore recommended

that the Correctional Service of Canada implement a pilot needle exchange program in three or more correctional facilities, at least one of which should be a women's facility, by June 2004. The results of the pilot project should be monitored, disclosed and assessed within two years.⁴

The Commission had previously expressed its support for a pilot needle exchange program in federal

prisons,⁵ but its formal recommendation to implement such programs in a number of prisons is a welcome new development.

—Ralf Jürgens

Portugal: Report recommends needle exchange or safe injection sites

A report released in late 2003 by Portugal's Justice Ombudsman (Provedor de Justiça) recommends that Portugal set up needle exchange programs or safe injection sites in prisons.¹

According to the Ombudsman's report, widespread drug use is leading to rising HIV rates among Portugal's 14,000 prisoners. Fourteen percent of prisoners are living with HIV and 396 prisoners have AIDS. As well, 11 percent of prisoners who participated in a study admitted to having injected drugs while in prison,² with more than three-quarters of them sharing their needles — creating an ideal environment for the spread of HIV.

The report recommends that the government establish pilot needle exchange programs or safe injection sites in prisons to slow the spread of HIV,³ and makes reference to Spain's positive experience with the introduction of prison needle exchange programs.

As reported by Agence France Press,⁴ the recommendation was immediately backed by Portugal's lawyers association and by former UN General Assembly President Diogo Freitas do Amaral, who currently chairs a commission on prison reform in Portugal. Justice Minister Celeste Cardona, however, has rejected the proposal. Instead, government policy will continue to focus on addiction

treatment programs, including methadone maintenance treatment, she said. Fernando Negrao, head of Portugal's Drugs Institute, a branch of the health ministry, argued that injection rooms could be effective but only after prisons become less crowded.

This is not the first time that the establishment of safe injection sites in prisons has been recommended. As previously reported in the *Review*, at the time the Spanish government ordered the distribution of clean needles in all prisons, a Spanish labour union stated that it would have preferred the creation of safe injection rooms instead of needle exchange programs.⁵

—Ralf Jürgens

¹ Canadian Human Rights Commission. *Protecting Their Rights. A Systemic Review of Human Rights in Correctional Services for Federally Sentenced Women*. Ottawa: The Commission, December 2003. Available at www.chrc-ccdp.ca/Legis&Poli/IndexFSW_FSF.asp?l=e.

² *Ibid* at 37-38, with many references.

³ *Ibid* at 38.

⁴ *Ibid* (recommendation 4).

⁵ Canadian Human Rights Commission. *Annual Report*. Ottawa, Supply and Services Canada, 1995, at 34; 1996, at 38-39; 1997, at 31-32; and 1998, at 27-28.

¹ O Provedor de Justiça. *As nossas prisões*. Apresentação do Relatório sobre a Sistema Prisional/2003. 13 November 2003. Available at www.provedor-jus.pt/publicacoes/Rel2003Prisoas/welcome.html.

² *Ibid* at 14.

³ *Ibid* at 15.

⁴ Levi Fernandes, Agence France Presse, 24 December 2003.

⁵ Spain: Government orders distribution of clean needles in prisons. In: R. Jürgens. HIV/AIDS in prisons: new developments. *Canadian HIV/AIDS Policy & Law Review* 2002; 6(3): 13-19 at 16-17.

Canada: Coroner's inquest into the methadone-related death of a prisoner

A coroner's jury made 14 recommendations at the conclusion of an inquest into the death of Sonia Faith Keepness, a 37-year-old inmate at Prince Grove Correction Centre in Prince Albert, Saskatchewan.

The jury concluded that Keepness died on 19 February 2002 from what was likely a combination of methadone and Librium, a tranquilizer with sedative-type effects.¹ She took a "one-time dose" of methadone by ingesting the vomit of two fellow inmates who had regurgitated their prescribed methadone.² The two inmates who use methadone as treatment for drug addictions were subsequently sentenced for drug trafficking.³ The Prince Albert City Police reported at the inquest that it was a common occurrence for inmates to receive their methadone dose and then regurgitate the medication for other inmates to consume, in exchange for favours.⁴

In Saskatchewan, under The Coroners Act, 1999, an inquest must be held whenever an inmate in a correctional facility dies.⁵ The coroner's jury made recommendations to prevent similar deaths, including recommending education for prisoners and staff regarding addictions and the use of illicit drugs; regular and scheduled visits to the centre by a psychiatrist; and a review of the methadone programs used in Saskatchewan correctional facilities, with a focus on precautions related to ingestion/absorption rates.⁶ Saskatchewan's Ministry for Corrections and Public Safety has since reported changes in their administration of methadone, including ensuring that inmates are

kept in a room under observation for an hour after taking their daily methadone.⁷

– Grant Holly

Grant Holly is a first-year student at the Faculty of Law, McGill University.

¹ S Tipper: Drugs likely killed inmate: Methadone, Librium found in system: expert. 4 March 2003, online at Injustice Busters (www.injusticebusters.com/2003/Keepness_inquest.htm).

² Ibid.

³ Ibid.

⁴ Ibid.

⁵ SS 1999, c 38.01, as amended, s 20.

⁶ Jury Report – Saskatchewan Justice.

⁷ S Tipper: No overdoses a priority: Inmate death to methadone a concern: official. 12 March 2003, online at Injustice Busters (www.injusticebusters.com/2003/Keepness_inquest.htm).

Canada: Court affirms that prisoner health information must be treated as private and personal

On 8 April 2003, the Federal Court of Canada – Trial Division ruled that Correctional Services Canada (CSC) does not have a duty to warn an inmate of the potential violence or health hazards posed by a cellmate in the absence of clear and foreseeable danger.

The *Farrows-Shelley*¹ case arose out of a fight on 23 July 1999 between two inmates placed in a double-bunking situation at Warkworth Institution.

The plaintiff sued CSC for negligence. He alleged that he suffered minor cuts and lacerations from the altercation, as well as anxiety and

CSC has no reason or authority to investigate, verify, or disclose a prisoner's health information upon arrival at a new institution.

emotional distress because of fear that he may have contracted hepatitis and HIV from his cellmate, whom he suspected was infected. The court stated that the onus was on the plain-

tiff to prove (1) that CSC owed him a duty to warn him of potential violence or health hazards; and (2) that there was a breach of the duty based on the limited and particular facts of the case. A CSC witness indicated that all inmates are pre-cleared prior to changing institutions and bunk placement, and that there are offenders with HIV infection in the open prison population, much like in the general population.

The court decided that CSC did not have a duty to warn, given that the plaintiff failed to provide evidence that his cellmate was infected with either hepatitis or HIV or had any undue tendencies to violence. Moreover, the court made a finding of fact that the plaintiff's behaviour provoked his cellmate, based on the plaintiff's candid dislike for his cellmate and suspected inconsistency

between the plaintiff's demeanour in court and his affidavit. The court also affirmed CSC's policy that an inmate's medical information is treated as private personal information. Under the policy, the prisoner's right to privacy is balanced with the protection of the prison population through the use of universal precautions to address exposure to bodily fluids. The court said that CSC has no reason or authority to investigate, verify, or disclose a prisoner's health information upon the prisoner's arrival at a new institution. The court concluded that the plaintiff failed to prove that the duty was owed and no liability was accordingly found.

– *Grant Holly*

¹ *Farrows-Shelley v Canada* 2003 FCT 415.

Other developments

Statistics on HIV/AIDS in prisons in the US

The Bureau of Justice Statistics, US Department of Justice, recently released its annual report on HIV/AIDS in prisons in the US.¹ The report provides the number of HIV-positive and active AIDS cases among prisoners held in each state prison system and the federal prison system at the end of 2001. It includes data on

the number of AIDS-related deaths, a breakdown for women and men living with AIDS, and comparisons with AIDS rates in the general population. Historical data on AIDS cases are presented from 1995, and on AIDS deaths from 1991. Highlights include the following:

- On 31 December 2001, 22,627 state inmates (two percent of state prison inmates) and 1520 federal

inmates (1.2 percent of federal prison inmates) were known to be infected with HIV. The number known to be HIV-positive totaled 24,147, down from 25,333 at the end of 2000. New York had the highest percentage of inmates known to be HIV-positive (8.1 percent), followed by Rhode Island (4.4 percent) and Florida (3.6 percent). Four states (Vermont, North Dakota, South

Dakota, and Wyoming) reported 10 or fewer known HIV-positive inmates in their prisons.

- A greater percentage of female than male inmates is HIV-positive. Overall, 1.9 percent of male inmates and 2.9 percent of female inmates in state prisons were known to be HIV-positive. In nine states, more than five percent of all female inmates were known to be HIV positive. In New York, 14.9 percent of female inmates were known to be HIV-positive; in Rhode Island, 12.1 percent; in Nevada, 12 percent. New York (with 7.8 percent) was the only state with more than five percent of male inmates known to be HIV-positive.
- Of those known to be HIV-positive in all US prisons at the end of 2001, 5754 were confirmed AIDS cases, up from 5696 in 2000. Among state inmates, 0.5 percent had AIDS; among federal inmates, 0.4 percent. The rate of confirmed AIDS cases in state and federal prisons was more than three times higher than in the total US population.
- During 2001, 256 state prisoners died from AIDS-related causes, up from 185 in 2000. This increase was the first since the number of AIDS-related deaths peaked at 1010 in 1995.
- In 2001, eight percent of state inmate deaths were attributed to AIDS, down from 32 percent in 1995. Among federal prisoners, 22 died from AIDS-related causes, up one from 2000.

The report is based on the 2001 National Prisoners Statistics (NPS). Data from the NPS were provided by the departments of corrections in 50 states and the District of Columbia, and by the Federal Bureau of Prisons.

Australia: Hepatitis C “sweeps” prisons

According to a report by health reporter Ruth Pollard,² a hepatitis C (HCV) epidemic is “sweeping” prisons in New South Wales (NSW), Australia. Sixty percent of women and 40 percent of men in the state’s prisons are reported to be infected with HCV. Michael Levy, director of population health for the NSW Corrections Health Service, said that there are 4000 people with HCV in the state’s prisons at any one time. There are now specialist HCV clinics in each of the state’s 29 prisons, providing and monitoring treatment and organizing liver biopsies for prisoners.

New web resource on HIV, hepatitis, and prisons

The Access to Health Care for the Incarcerated initiative of the [US] AIDS Treatment Activists Coalition (ATAC) has the goal of “increasing access to health care for incarcerated people through strategy coordination, information sharing, training and advocacy for allied individuals, groups, and communities.” The initiative recently established a list of 40 of the best websites with information on HIV/AIDS, HCV, and prisons.³

US: CDC promotes rapid HIV testing in short-term facilities

The [US] Centers for Disease Control and Prevention (CDC) has launched a two-year corrections demonstration project to provide HIV rapid testing for prisoners entering short-term prison facilities in Florida, Louisiana, New York, and Wisconsin. The goal is “to provide rapid HIV tests to people booked into jails for a relatively short time – three or four days or a few weeks – and to link HIV positive offenders to services on the outside upon release.”⁴ These people have traditionally not been offered HIV testing, and the initiative is seen as an opportunity to provide them with HIV testing and counselling, and to link them with care and treatment and preventative services. The demonstration project is part of the CDC’s Advancing HIV Prevention initiative.

– Ralf Jürgens

¹ Bureau of Justice Statistics Bulletin. *HIV in Prisons, 2001*. Washington: US Department of Justice, Office of Justice Programs, January 2004 (NCJ 202293). Available at www.ojp.usdoj.gov/bjs/abstract/hivp01.htm.

² R. Pollard. Hepatitis C epidemic sweeps NSW prisons. Available at www.smh.com.au/articles/2004/01/11/1073769455690.html?from=storyrhs.

³ The goal statement and the list of best websites can be found on the ATAC website at www.atac-usa.org/Prisons.html.

⁴ CDC promotes rapid HIV testing in short term facilities. *Positive Populations* 2003; 5(3): 5.

HIV/AIDS IN THE COURTS – CANADA

This section presents a summary of Canadian court cases relating to HIV/AIDS or of significance to people with HIV/AIDS. It reports on criminal and civil cases. The coverage aims to be as complete as possible, and is based on searches of Canadian electronic legal databases and on reports in Canadian media. Readers are invited to bring cases to the attention of Glenn Betteridge, editor of this section, at gbetteridge@aidslaw.ca.

Limits on CPP survivor benefits for same-sex couples unconstitutional

On 19 December 2003, the Ontario Superior Court of Justice declared the federal government's Canada Pension Plan¹ (CPP) survivor benefits regime as it applied to same-sex couples unconstitutional. Under the law, survivors in same-sex relationships could not receive benefits if their partner had died prior to 1 January 1998, while no similar restriction was imposed on opposite sex-relationship survivors. In *Hislop v Canada*,² Justice Macdonald found this cut-off date to be unconstitutional because it denied gay and lesbian survivors equality of the law.

Background

The *Hislop* case was the consolidation of two actions against the federal government – one originally brought in British Columbia, the other in Ontario – to have same-sex survivor benefits extended to those applicants whose partners died prior

to 1 January 1998.³ This cut-off date was created by the federal Modernization of Benefits and Obligations Act⁴ (MOBA), which came into effect on 31 July 2000 and which amended the CPP to provide same-sex common-law couples with survivor's benefits. (The MOBA

amended more than 60 laws to put same-sex common-law couples on the same legal footing as heterosexual common-law couples.)

Survivor benefits under the CPP are monthly payments to a person whose spouse or common-law partner has died. To be eligible, the deceased must have made sufficient CPP payments while alive, and the surviving partner must be over 35 years of age (unless he or she is disabled or is the primary caregiver of a child of the deceased).⁵ Payments normally start one month after the death of the survivor's partner. Until the MOBA was passed, these bene-

fits were unavailable to same-sex common-law couples. However, the cut-off date of 1 January 1998 meant that many same-sex survivors, many of whom were people living with HIV/AIDS, were ineligible.

Significantly, under the CPP as amended by the MOBA, same-sex partners who met the eligibility criteria for survivors benefits (ie, their partners died on or after 1 January 1998) were only entitled to be paid benefits from July 2000, regardless of their partner's actual date of death or the date on which their application for benefits was completed. In contrast, opposite-sex survivors are entitled to receive benefits effective as early as the month of the date of death, but in no cases earlier than 12 months prior to the date the application for benefits was received.⁶

The arguments

Each of the representative plaintiffs in *Hislop* was the survivor of a same-sex relationship whose partner had died between 1985 and 1 January 1998.⁷ They argued that the 1 January 1998 cut-off date for eligibility, and the July 2000 commencement date for payment, were unjustifiable and unconstitutional infringements of the equality rights of gay men and lesbians. They asked the court to extend the entitlement of same-sex survivors back to 17 April 1985 and to strike down the arbitrary limitation of the payment date. The 17 April 1985 date is significant because on that day the section 15 equality rights guarantees under the Canadian Charter of Rights and Freedoms came into force.⁸

The plaintiffs also argued that the government had breached the fiduciary duty it owed to the plaintiffs. A fiduciary duty exists in relationships

where it is mutually understood that one party will act in the best interest of the other. They further contended that the government had been unjustly enriched by collecting CPP payments from deceased members of same-sex couples and by not redistributing the money to the surviving partners. Finally, the plaintiffs argued that they should be awarded \$20,000 each in symbolic damages, claiming that the federal government had acted in bad faith by treating them arbitrarily and deceitfully.⁹

In response, the government said that the cut-off date was the product of a distinction based on time rather than sexual orientation. It claimed “that it was only in the mid 1990s that same sex relationship recognition reached the ‘radar screen’ of Canadian society.”¹⁰ The provisions of the MOBA, according to the government, were therefore in accordance with the evolution of social values. The government also argued that there was no objection from gay or lesbian advocates during the passage of the legislation.

The decision

The court took as its starting point the Supreme Court's decision in *Egan v Canada*.¹¹ In *Egan*, the court ruled that the exclusion of same-sex partners from the old age security pension was an infringement of s 15(1) of the Charter. The court therefore made sexual orientation an “analogous ground” under s 15(1), meaning that although sexual orientation is not explicitly mentioned in the section as an impermissible basis of discrimination, it would thereafter be considered as one. In *Hislop*, Macdonald J found that because same-sex common-law couples must receive the same treatment under the

law as their opposite-sex common-law counterparts, the cut-off date of 1 January 1998 was discriminatory.

In its arguments to the court, the government said that to strike the 1 January 1998 cut-off date would be to apply the Charter retroactively.¹² Macdonald J, however, held that this was an incorrect interpretation of retroactivity. While it is certainly wrong to apply a new law to something that happened in the past, Macdonald J said, the distinction in this case is that “the application of the Charter is not retroactive if applied to discrimination suffered after the passage of the Charter, if such discrimination is based on one's status.”¹³ Simply stated, Macdonald J determined that “If the law is truly to

“If the law is truly to be in conformity with the Charter, a discriminatory bar to same sex survivors must be treated as if it never existed.”

– Justice Macdonald

be in conformity with the Charter, a discriminatory bar to same sex survivors must be treated as if it never existed.”¹⁴

The court rejected the government's contention that same sex-relationship rights were not a social phenomenon until shortly before the passing of the MOBA. It also repudiated the government's argument that advocates of equal rights for the gay and lesbian communities had supported all of the MOBA's provisions.

However, it did not find that the government had breached a fiduciary duty, because in its opinion the mutual understanding required to establish such a relationship was lacking.¹⁵ Finally, the court denied the claim that the government had been unjustly enriched, because CPP payments are held strictly in a consolidated fund for CPP purposes.¹⁶

The remedy the court ordered was to strike the offensive provisions of the CPP, effectively giving survivors of same-sex relationships the same entitlement to survivor benefits as opposite-sex couples. Further, the court constitutionally exempted the plaintiffs from the general CPP provisions limiting the payment of arrears to one year prior to the date of application for benefits.¹⁷ However, the court declined to award symbolic damages, as had been requested by the plaintiffs. The ruling was made effective immediately. The federal government is appealing the decision to the Court of Appeal for Ontario.

Comment

This decision is extremely positive because many people whose same-sex partners have died as a result of HIV/AIDS have been ineligible for CPP survivor benefits until now, or did not receive their full entitlement. In fact, a number of the representative plaintiffs in the case had lost partners to HIV/AIDS or were living with HIV/AIDS. Although it is unfortunate that the claimants realized no additional symbolic benefits, the court's finding is nonetheless a significant victory for equal rights.

— Gord Cruess

Gord Cruess is a first-year student at the Faculty of Law, McGill University.

¹ RSC 1985, c C-8 (CPP).

² *Hislop v Canada (Attorney General)*, [2003] OJ No 5212 (QL) (OSCJ).

³ The two cases are *Brogaard v Canada (Attorney General)*, [2002] BCJ No 1775 (QL) (BCSC), which originated in British Columbia, and *Hislop v Canada*

(*Attorney General*), [2002] OJ No 2799 (QL) (OSCJ), which arose in Ontario. For more background information on these cases and on the CPP and the MOBA, see R. Carey, *Discrimination in same-sex survivor amendments to the Canada Pension Plan*, *Canadian HIV/AIDS Policy & Law Review* 2002; 7(2/3): 71-72; and G. Betteridge, *CPP same-sex survivors class action to proceed on a national basis*, *Canadian HIV/AIDS Policy & Law Review* 2003; 8(1): 67.

⁴ SC 2000, c 12.

⁵ CPP, s 44.

⁶ CPP, s 72(1).

⁷ *Hislop*, supra, note 2 at para 2.

⁸ Part I of the Constitution Act, 1982, Schedule B to the Canada Act 1982 (UK), 1982, c 11 (Charter). Section 15 (1) of the Charter reads: "Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability."

⁹ *Hislop*, supra, note 2 at para 6.

¹⁰ *Ibid* at para 63.

¹¹ *Egan v Canada*, [1995] 2 SCR 513.

¹² *Hislop*, supra, note 2 at para 2.

¹³ *Ibid* at para 98.

¹⁴ *Ibid* at para 103.

¹⁵ *Ibid* at para 124.

¹⁶ *Ibid* at para 126.

¹⁷ *Ibid* at para 120.

Supreme Court upholds criminal prohibitions on possession of marijuana for recreational use

In two recent decisions, *R v Malmo-Levine* and *R v Caine* (decided together)¹ and *R v Clay*,² the Supreme Court of Canada ruled that the criminal prohibition on marijuana possession, in the absence of a regulatory exemption for medical purposes, is constitutional.

The Supreme Court heard the cases together, and released its decision on both cases on the same day. In each case, the accused were prosecuted for

possession of marijuana under the former Narcotic Control Act.³ *Malmo-Levine* and *Clay* were also charged with possession for the purposes of

trafficking. The principle issue before the Supreme Court was whether the criminal prohibition against the possession of marijuana infringed the accused's rights to liberty and security of the person protected under section 7 of the Canadian Charter of Rights and Freedoms.⁴ The liberty interest implicates a person's right to make

decisions without fear of imprisonment, while the security of the person interest implicates the individual's right to make decisions about his or her bodily integrity.

While the court found that these 7 rights are infringed by the potential of incarceration for marijuana possession, it also held that the availability of imprisonment as a legal sanction is consistent with the principles of fundamental justice.⁵ The court found that because of the potential harms associated with marijuana use and proliferation, "the prohibition on marijuana possession is neither arbitrary nor irrational."⁶

Comment

Had these appeals been successful, people who use marijuana for medical purposes, including people living with HIV/AIDS, may have been disinclined to apply for or renew exemptions under the Marijuana Medical Access Regulations.⁷ As it stands, those who require exemptions will still have to go through the onerous application and annual renewal processes.⁸

Despite the court's affirmation that it is within the scope of Parliament's power to criminally sanction possession, there have been recent legislative moves that, if implemented, would decriminalize the possession of small amounts of marijuana. Bill C-38, An Act to Amend the Contraventions Act and the Controlled Drugs and Substances Act, would replace criminal charges with scaled fines for possession of up to 15 grams of marijuana. The bill, while stopping short of full legalization, would remove the threat of potential jail time for possession of small amounts and would lower the fines that are currently in place.⁹ However, the bill died on the House of Commons order paper in November 2003, and although Prime Minister Martin has affirmed that he will introduce similar legislation, he has suggested that the bill requires fine-tuning in terms of decreasing the 15-gram limit, increasing the fines currently proposed, and mandating harsher penalties for producers.¹⁰

— Gord Cruess

¹ *R v Malmo-Levine; R v Caine* [2003] SCJ No 79 (QL).

² *R v Clay* [2003] SCJ No 80 (QL).

³ RSC 1985, c N-1.

⁴ Part I of the Constitution Act, 1982, Schedule B to the Canada Act 1982 (UK), 1982 c 11 (Charter). Section 7 of the Charter reads: "Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice."

⁵ *Clay*, supra, note 2 at para 3.

⁶ *Malmo-Levine; Caine*, supra, note 1 in the preamble.

⁷ SOR/2001-227, as amended by SOR/2003-387.

⁸ In a recent Ontario Court of Appeal decision, *Hitzig v Canada* [2003] OJ No 12 (CA) (QL), sections of the Medical Marijuana Access Regulations (MMAR) were held to represent an unconstitutional barrier to accessing marijuana for those with a recognized medical need. The MMAR's second-specialist requirements to obtain an authorization to possess were struck and the court lifted some of the restrictions associated with designated-person production licences. For more information on the *Hitzig* decision and the MMAR, see G Cruess. Ontario court affirms that medical marijuana regulations are unconstitutional. *Canadian HIV/AIDS Policy & Law Review* 2003; 8(3): 53-56.

⁹ D Thaczuk. Ottawa moves to decriminalize small amounts of marijuana. *Canadian HIV/AIDS Policy & Law Review* 2003; 8(2): 22-23.

¹⁰ J Brown. Martin to roll his own pot bill. *Globe and Mail*, 18 December 2003.

Ontario Securities Commission has authority to investigate viatical settlement purchase program

On 27 October 2003, the Ontario Superior Court of Justice held that the Ontario Securities Commission (the Commission) has the authority to compel testimony and the production of written documents from parties that are not registered under the Ontario Securities Act (OSA). The finding in *Universal Settlements International, Inc v Ontario (Securities Commission)*¹ is important because it affirms the authority of the Commission to investigate businesses that might be engaging in the sale of illegal viatical settlements, an unregulated industry with potential negative impacts for people living with HIV/AIDS.

The facts

Ontario's Superintendent of Financial Services alleged that Universal Settlements International, Inc (USI) was engaging in the illegal trafficking of insurance policies. USI was charged with selling Ontarians "viatical settlement purchase programs."² Viatical settlements involve the

purchase of insurance policies from dying policyholders (“viators”) by a “purchaser.” Under these arrangements, the purchaser pays the viator a lump sum, determined according to the value of the policy. In exchange, the viator irrevocably designates the proceeds of the policy to the purchaser upon the viator’s death. In Ontario, viatical settlements are currently illegal unless the purchaser is a licensed insurer.³ The Superintendent of Financial Services alleged that the unlicensed USI was engaging in these settlements with people suffering from illnesses such as HIV/AIDS.⁴

On 6 December 2003, the Financial Securities Tribunal held that USI’s conduct did not amount to selling insurance in Ontario. The Ontario Securities Commission nonetheless requested certain information from USI in order to determine whether USI’s conduct fell under the ambit of the OSA. After the Commission refused USI’s request to quash the investigation, USI applied to the court challenging the Commission’s authority to investigate USI’s activities.

The judgment

The question before the court turned on the scope of the Commission’s powers of investigation and review under the OSA. USI argued that the Commission’s investigative powers under section 11 of the OSA are limited to regulating securities, meaning that “the Commission would have to establish conclusively that USI deals in a ‘security’ as defined by the Act” in order to investigate its activities.⁵ The Commission argued that it had the authority to investigate dealings that, given its expertise as the OSA’s

regulatory agency, it suspected to be in potential violation of the Act.

Significantly, the court determined that the law relating to viaticals was by no means settled, including the fundamental question of whether or not viatical settlement schemes involve trading in securities. The court found that the Commission’s decision to investigate USI merited the court’s deference. This finding was based on the court’s appreciation of the Commission’s position as an expert in the regulation of capital markets and its important public role.⁶

Comment

The deference shown by the Ontario Superior Court to the Commission in its role as protector of the public interest represents a small but significant protection for people living with HIV/AIDS. The court’s decision affirms that securities regulators have broad discretion to investigate companies who may be engaging in questionable transactions with people faced with terminal illness, such as HIV infection. Although the viatical industry in Canada is relatively small compared to that in the United States, it is not insignificant, and the potential for harm to individuals is great. In this case, the Commission alleged that USI has customers in Ontario, Nova Scotia, British Columbia, and Alberta, and that USI’s sales to Ontario residents alone amount to about \$1,500,000 per annum.

Contracts between unlicensed purchasers and insurance policyholders are illegal. Under the common law, illegal contracts are unenforceable. This means that if the purchaser failed to make a full payment for the

policy, the viator would potentially have no recourse in the courts to recover the payments that were unaccounted for. As Justice Greer wrote in the case, “It can be argued that the sector of the public involved in these viatical settlements is the most vulnerable, that is people who are ill, many of whom are dying and in need of money.”⁷ People with HIV/AIDS who are poor are especially vulnerable to unlicensed companies that engage in the business of viatical settlements. The case also highlights the need for provincial and territorial governments and regulators to consult with all interested parties, including people living with HIV/AIDS, about the legal status and regulation of the viatical industry.⁸

— Gord Cruess

¹ *Universal Settlements International, Inc v Ontario (Securities Commission)* [2003] OJ NO 4274 (QL).

² *Ibid* at para 3.

³ For more information on viatical settlements, see R Carey, Ontario to develop a viatical industry, *Canadian HIV/AIDS Policy & Law Review* 2001; 6(1/2): 32-33. Ontario has proposed new regulations that would allow any company to apply for a licence to trade in viatical settlements; see A Rich, Ontario proposes to regulate viatical settlements, *HIV/AIDS Policy & Law Review* 2003; 8(3): 29-30.

⁴ *Universal Settlements International*, *supra*, note 1 at para 3.

⁵ *Ibid* at para 14.

⁶ The three primary goals of the Ontario Securities Commission’s mandate are to “protect investors from unfair and fraudulent practices,” to “foster fair and efficient capital markets,” and to “maintain public and investor confidence in the integrity of those markets.” See the Commission’s website at www.osc.gov.on.ca for more information.

⁷ *Universal Settlements International*, *supra*, note 1 at para 15.

⁸ In Ontario, the Financial Services Commission consulted interested stakeholders and drafted regulations regarding the viatical industry, but has not taken the necessary legislative steps to bring the regulations into force. See A Rich, *supra*, note 3.

HIV/AIDS IN THE COURTS - INTERNATIONAL

This section presents a summary of important international cases relating to HIV/AIDS or of significance to people living with HIV/AIDS. It reports on civil and criminal cases. Coverage is selective. Only important cases or cases that set a precedent are included, insofar as they come to the attention of the Review. Coverage of US cases is very selective, as reports of US cases are available in *AIDS Policy & Law* and in *Lesbian/Gay Law Notes*. Readers are invited to bring cases to the attention of Glenn Betteridge, editor of this section, at gbetteridge@aidslaw.ca.

Developments in South African law on HIV/AIDS

South Africa has a powerful legal framework that offers high levels of protection to people living with HIV/AIDS, yet discrimination against people living with HIV/AIDS continues to be widespread in South African society. Court cases decided in 2003 regarding children's issues and health care testify to this ongoing discrimination, and to the potential of the South African legal system to uphold the rights of people living with HIV/AIDS.

Children's issues

As the epidemic develops in South Africa, issues relating to children and the impact of HIV are gaining prominence. The two cases described below illustrate some of the com-

plexities involved in children's rights and HIV/AIDS.

The right to equality in access to education

The Buccleuch Montessori Nursery School case¹ garnered much publici-

ty when it was argued in September 2002. The case concerned the right of Tholakele Nkosi, then three years old, to attend a private nursery school. The applicant in the case, Karen Perreira, Tholakele's foster mother, had elected to disclose

Tholakele's HIV status to the school, believing that it was in the child's best interest for the school to be aware of her medical condition.

The response of the school was surprising in the context of South Africa's mature and widespread HIV/AIDS epidemic, where awareness of the modes of transmission has been shown to be high. The school expressed fears about the risk of transmission to other children as a result of possible biting, scratching, insect bites, and sharing sweets. The school also indicated that it did not consider itself equipped to admit a child with HIV because none of its teachers had received any training on how to deal with HIV-positive children. In order to counter these allegations, expert affidavits dealing with the risks of HIV transmission in the school setting, evidence regarding the non-discrimination policy of the Department of Education, and international case law were put before the court.

A dispute existed between the parties as to whether Tholakele's application for admission was actually rejected. However, the school conceded that a recommendation had been made to defer the application until such time as the school considered itself ready to admit children with HIV, and until Tholakele was "past the biting stage." The lawyers for the child argued that, on its own, the deferral of Tholakele's application constituted unfair discrimination against the child.

Judge Lucy Mailula found that since the school had not made a final decision to exclude Tholakele, its conduct did not amount to unfair discrimination. The judge did not deal with the implications of the recommendation to defer Tholakele's

admission or with the discrimination inherent in such conduct, and dismissed the application with costs.

The judgment may perpetuate discrimination because it allows a school to exclude a child with HIV as long it defers the application rather than rejects it outright.

In the view of the AIDS Law Project (ALP), an organization in South Africa that fights human rights abuses and provides legal services to people in need, the judgment may perpetuate discrimination because it allows a school to effectively exclude a child with HIV as long it defers the application rather than rejects the child outright. The judgment provides no guidance as to the basis on which such a deferral may take place, how long the application may be deferred, and what steps a school should take to accommodate children with HIV. The judgment may also serve as a precedent for other settings where service providers wish to exclude people living with HIV/AIDS. The judgment has been appealed.

Children and consent to HIV testing and treatment

As of 2002, 13 percent of children between two and 14 years of age in South Africa had lost a mother, a father, or both parents.² The issue of consent to HIV testing and treatment will therefore become increasingly problematic – especially in the con-

text of the South African government's recent commitment to the rollout of antiretroviral medications (ARVs) in the public sector.

South African law requires that parental consent be obtained before any medical treatment can be given to a child less than 14 years of age. The Child Care Act permits the Minister of Social Development to consent to treatment in the absence of consent from a parent or legal guardian. As well, a medical superintendent may consent in urgent cases.³ The High Court,⁴ as the upper guardian of all children, may also be approached to give consent.⁵

The Wits Paediatric HIV Working Group (WPHWG) provides treatment and care to children in the public sector and to children and infants in children's homes. Children's homes are state-run or -subsidized homes where children in need are cared for. Not all the children who live in children's homes are orphans. Children can be placed in these homes only in accordance with the procedures set out in the Child Care Act. Increasing numbers of children with HIV who require treatment and care are presenting at hospitals without parents or legal guardians. For these children, there is no person who is legally capable of providing consent to treatment. A similar situation has arisen in children's homes where there are significant numbers of children, particularly newborn babies, who have not been lawfully placed in the custody of the children's homes.

The WPHWG seeks to provide a high level of treatment and care to vulnerable, orphaned children, and is concerned about how the requirement of consent could be addressed. It was the view of the WPHWG that

consent plays a crucial role in empowering patients and their caregivers to participate in decisions about their health, while also protecting health-care workers.

In 2003, the ALP took legal proceedings in three cases that dealt with children and consent. The first two merely sought permission from the High Court for five orphans without legal guardians to begin antiretroviral treatment.⁶ Although both applications were successful, it was clear that it would be difficult, time-consuming, and expensive to approach the High Court for each child in respect of whom consent could not be obtained.

The ALP then attempted to use mechanisms created by the Child Care Act that allowed for ministerial consent to be obtained where parental consent could not. The

Consent plays a crucial role in empowering patients and their caregivers to participate in decisions about their health.

Minister of Social Development responded promptly to the initial request and gave his permission for five children named in the letter to receive treatment. However, he failed to respond to any further requests. As a result of the Minister's failure to act, the ALP made an application to the Johannesburg High Court.

The application attempted to create a mechanism that would facilitate the care of these children, without

eroding the need to obtain consent. The remedy sought was much broader in scope than the previous applications. The order was granted on 5 December 2003. It permitted doctors associated with the WPHWG to obtain consent from the person who has daily care of the child, once the doctors have certified that the test or treatment is in the best interests of the child.⁷ This approach is in line with the current proposals in the Children's Bill (a draft statute that has not yet been enacted) that give limited legal recognition to caregivers and allows them to provide consent to medical treatment for the children they are looking after.

Although the latter case represents an important victory for children, its application is limited to the WPHWG and will not help doctors who are not members of the WPHWG. It is unlikely that the Children's Bill will become law in the near future, so it is extremely important that the issue of consent be dealt with in the interim. If it is not, doctors who treat children with HIV will be forced to either withhold the benefits of ARVs from children without legal guardians, or to act without consent. Neither situation is desirable.

Health care

Complaints against health-care workers

VRM v The HPCSA,⁸ a key case dealing with the role of the Health Professions Council of South Africa (HPCSA) in regulating the medical profession, concerned a pregnant woman with HIV who was tested during her pregnancy without her consent. The doctor who performed the test did not disclose the results of

the test to his patient, and failed to advise her of the steps she could take to reduce the risk of perinatal HIV transmission. The patient delivered a stillborn baby and was advised that she had HIV shortly after the birth.

The patient filed a complaint with the HPCSA. Although the doctor conceded that he had tested the patient without her consent and had not disclosed her test result, the HPCSA declined to convene a disciplinary hearing. Its Committee of Preliminary Enquiry accepted the doctor's version – that he had acted “out of compassion” – and declined to take the matter any further. The ALP brought an application to the High Court for review of the Committee's decision. The court, in a judgment handed down in 2002, agreed with the findings of the Committee. The ALP appealed the High Court's decision.

The appeal court criticized the failure of the HPCSA to adequately consider the facts of the case and indicated that the procedures of the Committee of Preliminary Enquiry were flawed. The judgment examined the role of this committee and indicated that it did not have the power to merely accept the version of the doctor over that of the patient, which it routinely does, unless the evidence provided by the doctor is corroborated. The matter has been referred back to the HPCSA for proper consideration.

During the 10 years of its existence, the ALP has brought many complaints against health-care workers to the HPCSA. Unfortunately, none of the complaints has been adequately considered. The ALP hopes that some of these cases will now be reconsidered in light of this judgment.

A civil claim for damages against the doctor is pending.

Medical aid schemes and “material non-disclosure”⁹

Medical aid schemes are a private form of medical insurance whereby members pay a monthly premium and receive certain medical benefits in exchange. The Medical Schemes Act gives medical aid schemes the power to cancel the membership if the person withheld “material information” from the scheme at the time of the member’s application.¹⁰ Yet the Act does not provide guidance as to what constitutes “material information.” In 2003, as a result of a case brought by the ALP, the Appeal Board of the Council for Medical Schemes interpreted the term “material information” for the first time.

The ALP’s client, FA, successfully applied for membership in a medical aid scheme, Compicare, in July 2001. A few weeks after his acceptance, when he consulted a general medical practitioner for ongoing diarrhea, the doctor suggested an HIV test. FA tested positive for HIV. Two months later, FA was hospitalized for a chest problem. While he was in hospital, he developed a herpes zoster infection. Compicare phoned the hospital during FA’s hospitalization and the nursing sister unethically and unlawfully informed Compicare of FA’s HIV status. Soon after, Compicare informed FA that his membership had been terminated retrospectively because of his alleged failure to disclose “material information” to the scheme when he applied for membership. In subsequent correspondence, it became clear that the material information Compicare was referring to was FA’s HIV status. FA was adamant that he did not know

his HIV status at the time of the application, a fact that his doctor confirmed.

The ALP assisted FA by requesting that Compicare reinstate his membership, and by subsequently lodging a complaint with the Medical Schemes Council. The Registrar of Medical Schemes instructed Compicare to reinstate FA. Compicare appealed the Registrar’s decision. The Council of Medical Schemes reviewed the case and affirmed the Registrar’s decision. Compicare asked for the case to be heard by the Appeal Board of the Council for Medical Schemes. On appeal, Compicare argued that FA’s failure to disclose (a) his HIV status; and/or (b) that he was treated for a sexually transmitted infection (STI) in December 1999; and/or (c) that he had received medical treatment for sinusitis, bronchitis, and a laceration to his eye weeks before applying to Compicare; and/or (d) that he received medical treatment for a chest infection a week before applying for membership, amounted to material non-disclosure.

The Appeal Board decided in FA’s favour and ordered Compicare to reinstate his membership. In reaching its decision, the Appeal Board found that FA was under no obligation to disclose the fact that he had been treated for an STI 12 months prior to his application. The Appeal Board also found that information relating to the treatment of “acute conditions treatable immediately” and not related to a chronic condition, is not material and need not be disclosed. Finally, the Appeal Board found that chronic conditions may be regarded as material for purposes of disclosure.

The decision can be used to argue that medical aid schemes cannot

discriminate against members for not providing information about a medical condition that was diagnosed or treated 12 months before applying to a scheme, and was not present at the time of the application. This information is not regarded as material. In addition, there is a legal basis for arguing that acute conditions present at the time of application that are treatable immediately, and are not chronic, need not be disclosed to the scheme.

— Liesl Gertholtz and Marlise Richter

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¹ Karen Perreira v Sr Helga’s Nursery School and another; Case No 02/4377.

² O Shisana et al. Nelson Mandela/HSRC Study of HIV/AIDS: South African National HIV Prevalence, Behaviour Risks and Mass Media. Household Survey 2002. Cape Town: Human Science Research Council Publishers, 2002, at 67.

³ Act 74 of 1983, s 39.

⁴ There is at least one High Court in each province in South Africa.

⁵ Supra, note 3.

⁶ Ex parte application of Nigel Redman N.O. Case No 14083/03 and Ex parte application of Nigel Redman N.O. Case No 18476/03.

⁷ Case No 29172/03 (unreported)

⁸ Case No 1679/02, High Court of South Africa (Transvaal Provincial Division).

⁹ This section is a slightly revised excerpt from T Motebele, M Richter: Medical aid schemes, HIV status and “material non-disclosure.” South African Medical Journal 2003; 93(10): 775-776.

¹⁰ Act 131 of 1998, s 29.