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HIV Testing & Treatment of Children

In the last year, courts in Canada, the US, and the UK have decided cases in which child welfare authorities have disputed parents' decisions to refuse HIV testing or treatment for their children. This article reviews recent US developments regarding refusal of treatment, and reports the outcome of a recent UK decision compelling the HIV testing of a minor against her parents' wishes. It then provides an update on two recent Canadian cases concerning a parent's refusal to treat an HIV-positive child with antiretroviral therapy, and a brief overview of the current state of Canadian law on the issue of minors and medical treatment.

United States

As reported in the last issue of the *Newsletter*, in April 1999 an *Oregon* court refused to return a baby to the custody of an HIV-positive mother who indicated she would breast-feed the child. She argued that HIV does not cause AIDS and that breast milk cannot spread the virus; the court said the parents may choose to run that risk with the child, but that it could second-guess that decision.[1] Over the parents' objections about the side effects of treatment, the court also ordered six weeks of AZT treatments for the child as a prophylactic measure to prevent his infection.[2]

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

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Canadian Strategy on HIV/AIDS

HIV/AIDS and Children's Rights

Today, the majority of all new HIV infections occur among children and young people under 25 years of age, the people who were born and who have grown up during the AIDS epidemic. The epidemic is straining resources in already impoverished communities and creating new obstacles to the realization of children's rights to survival, development, and protection. The failure to ensure children's rights creates opportunities for HIV infection; at the same time, HIV/AIDS creates opportunities for the violation of children's rights. Advances in the realization of children's rights, including the implementation of the United Nations Convention on the Rights of the Child (UNCRC), are necessary to stem the growth of the AIDS epidemic.

We reproduce a fact sheet produced by the Interagency Coalition on AIDS and Development (ICAD) that summarizes available information on HIV/AIDS and children, and discusses the effect of HIV/AIDS on children's rights. The fact sheet also provides information about other, essential resources on HIV/AIDS and children.

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Comments?

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

CANADIAN HIV/AIDS POLICY & LAW NEWSLETTER

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

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

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

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

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

The Network is based in Montréal. We welcome new members. For membership information, contact Anne Renaud at <arenaud@aidslaw.ca>.

HIV Testing & Treatment of Children

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Previously, in November 1998, the *Maine* Supreme Judicial Court had unanimously upheld a lower court's decision that Valerie Emerson could refuse continued treatment with antiretrovirals for her four-year-old HIV-positive son.[3] The woman's three-year-old daughter, who had taken AZT monotherapy, had already died of AIDS-related pneumonia. Emerson had already discontinued medication herself. She attributed her son's healthy condition to her refusal to treat him with the recommended therapy, saying that his health deteriorated during the 10 weeks he had been receiving AZT.

The appellate court agreed with the lower court that, on the facts of this case, the state should not supersede Emerson in making medical treatment decisions for her son, noting that she was keeping an "open mind" about future resort to antiretroviral therapy should his condition worsen. The court ruled that the state had a burden of proving imminent danger that would "jeopardize [his] health and welfare" in order to terminate his mother's custody. However, the court cautioned that this decision might be reviewed should the child's condition or information about available treatments change.

> In September, the High Court in London ruled that a four-month-old girl born to an HIV-positive mother must be tested for the virus, against the wishes of her parents.

United Kingdom

In September 1999, the High Court in London ruled that a four-month-old girl born to an HIV-positive mother must be tested for the virus, against the wishes of her parents.[4]

The court's decision stated that the mother was diagnosed as HIV-positive in 1990 and has never taken antiretroviral therapy. The father, who has tested HIV-negative, practises alterative medicine. They contend that HIV is not the sole cause of AIDS. In July 1998, the mother became pregnant; she rejected advice to take antiretroviral medication during pregnancy and to deliver by caesarean section so as to reduce the likelihood of HIV transmission to the fetus. She continued to breast-feed the infant against medical advice,

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Please direct your enquiries to Éric Nolet at <enolet@aidslaw.ca>.

taking the position that the benefits of breast-feeding outweigh the risks.

Social workers for the Camden Council in north London invoked the 1989 *Children Act* to challenge the parents' refusal to have the infant tested. That statute prohibits the court from making any order unless it considered that to do so would be better for the child than to make no order. They sought the court-ordered testing so that the infant can receive treatment if infected. The court ordered a ban on publishing the identity of the parents and child, and held the four-day hearing in private.

Court-Ordered HIV Testing

Wilson J of the High Court ruled that the child must be tested, saying the case for overriding the wishes of the parents was "overwhelming" and that if the child were infected she had a right to the best treatment. He also suggested that, if the parents refused medical advice regarding treatment, further monitoring (including testing) might be ordered and, if the child's health suffered, possibly combination therapy. "This baby has rights of her own.... This case is not about the rights of the parents, and if, as the father has suggested, he regards the rights of a tiny baby to be subsumed within the rights of the parents, he is wrong."[5]

However, Wilson J indicated that he would not order the mother to stop breast-feeding, saying the law could not "come between the baby and the breast"[6] and that any such court order would be impossible to enforce. Wilson J made his ruling public in light of the "very legitimate public interest." Further private hearings to decide how, when, and where the child should be tested were to follow.[7]

The court eventually ordered the HIV test to be carried out in London on 24 September. A few days before this date, UK media reported that the parents had informed them they had left the country to avoid the testing.[8] The parents sought leave to appeal the decision, but did not appear before the Court of Appeal for the hearing of their application. On 21 September, the Court of Appeal upheld the High Court's ruling ordering the test.[9]

Reaction from HIV/AIDS Organizations

Commenting on the case, the National AIDS Trust and the Terrence Higgins Trust, two large AIDS organizations in the UK, publicly spoke of the value of recent developments in combination therapy.[10] Before the decision, the National AIDS Trust also issued a news release stating it is preferable for families and care workers to achieve consensus on such issues,

> but in situations where this proves impossible we would support a local authority in seeking an independent review on the best course of action for the child's wellbeing. At the end of the day the best interests of the child must be paramount in these cases and we believe that children have the right to receive the best HIV care available.[11]

Following the decision, the National AIDS Trust issued another news release regretting the necessity for court intervention but stating that

> a court may deem testing necessary on behalf of a child, where the child is unable to give consent itself and where the benefits of knowing the result are borne out by the weight of medical evidence. Enshrined in our statutes is the policy of acting in the best interests of the child. We believe that children have the right to receive the best HIV care available.[12]

The organization was also careful to point out that the decision

> does not given local authorities a "green light" to insist on compulsory testing in similar cases.... [I]n the vast majority of cases, families and their care workers agree on the best course of action for affected children.... It is critical that the policy of encouraging voluntary testing continues to underpin the UK's response to HIV. This is particularly important at a time when women are being offered voluntary HIV testing during antenatal care in order that women and their babies may benefit from recent medical advances.[13]

(In mid August, the NAT had welcomed the announcement by the Minister of Public Health that HIV tests would be suggested to all pregnant mothers in the UK as part of the routine battery of antenatal tests.[14]) The Terrence Higgins Trust, Europe's largest HIV/AIDS charitable organization, also welcomed the court's decision.[15]

However, the George House Trust, another HIV organization, opposed the court action by child protection authorities, arguing that

> nobody should be forcibly tested for HIV. Focusing only on potential benefits of treatment for the child overlooks the impact on the mother and the household. This is not in the interest of child or parent. Demanding routine testing and

> taking people to court to ensure testing risks driving HIV underground, making it less likely that people will access services. This is not in the interest of the public's health.... No one, local authority or otherwise, has the right to believe that their interest in a child can over-rule the informed consent of the parent.[16]

Canada

Recent Litigation in Montréal and British Columbia

At the end of August 1999, Sophie Brassard, a Montréal woman living with HIV for 13 years, sought an injunction from the Québec Superior Court preventing physicians from administering antiretroviral medications to her HIV-positive son. She argued that both she and her two HIV-positive sons have remained healthy while avoiding drugs she considers "highly toxic." According to Brassard, her father contacted child protection officials when her seven-year-old son contracted pneumonia resistant to normal antibiotics. The officials intervened, and the woman lost custody of her two sons. However, she applied to the court for an injunction against Montréal's Ste Justine Hospital administering the drugs.[17] The court did not grant the injunction because the hospital agreed to delay treatment pending a custody hearing that was scheduled for October 1999 (the hearing was later postponed to December). Brassard's application was supported by the US-based organization International Coalition for Medical Justice, which argues that HIV does not cause AIDS.[18] On 23 October, media reports indicated that Brassard had dropped her lawsuit.[19]

Canadian law has strongly affirmed the right to only receive medical treatment after providing "informed consent."

Also in October, the media reported that an HIV-positive Alberta woman living in British Columbia had gone into hiding in Alberta with her two infant sons. According to reports, she said she was told by her physician that social workers could remove her children from her custody if she breast-fed her newborn. She said she was subsequently ordered by social workers to get herself and her two children tested for HIV, and that if the children tested positive they would be administered antiretroviral drugs, even if she did not consent. The woman reportedly stopped breast-feeding but left BC for Alberta. According to press reports, she says she does not believe HIV causes AIDS, that "AZT is poison," and that parents should be given the final say in medical decisions for their children. She indicates that she herself has been HIV-positive for 15 years, and that the only time she has felt sick was when taking anti-HIV drugs for a month at her doctor's insistence.[20]

Child protection officials in both BC and Alberta were reported as saying that they would not impose mandatory testing and would not remove children from her custody for her refusal to have them undergo a test that is not mandatory. Alberta child protection authorities were reported as saying they would not intervene without a request from BC officials.[21]

Canadian Law on Minors and Medical Treatment[22]

Informed Consent in Making Treatment Decisions

Canadian law has strongly affirmed the right to only receive medical treatment after providing "informed consent," as affirmed in two leading 1980 decisions of the Supreme Court of Canada.[23] The health-care worker who treats someone without consent may be civilly and criminally liable, and may also be subject to professional discipline.

As courts have ruled in subsequent cases, a person's right to give informed consent to medical treatment necessarily includes the right to refuse such treatment, even if that treatment would likely save their life.[24] Canadian courts have strongly stated this conclusion:

> The right of a person to control his or her own body is a concept that has long been recognized at common law. The tort of battery has traditionally protected the interest in bodily security from unwanted physical interference.... No special exceptions are made for medical care, other than in emergency situations, and the general rules governing actions for battery are applicable to the doctor–patient relationship. Thus, as a matter of common law, a medical intervention in which a doctor touches the body of a patient would constitute a battery if the patient did not consent to the intervention. Patients have the decisive role in the medical decision-making process. Their right of self-determination is recognized and protected by law.[25]
>
> The fact that serious risks or consequences may result from

> a refusal of medical treatment does not vitiate the right of medical self-determination. The doctrine of informed consent ensures the freedom of individuals to make choices about their medical care. It is the patient, not the doctor, who ultimately must decide if treatment – any treatment – is to be administered.[26]
>
> It should not be forgotten that every patient has a right to bodily integrity. This encompasses the right to determine what medical procedures will be accepted and the extent to which they will be accepted. Everyone has the right to decide what is to be done with one's own body. This includes the right to be free from medical treatment to which the individual does not consent.[27]

Not only is the right to grant or refuse consent to medical treatment established in Canadian common law; it has also been considered to be constitutionally protected, as the Ontario Court of Appeal indicated in *Fleming*.[28]

The common law also recognizes, however, that in emergency situations where immediate treatment is required and the consent of the patient (or their substitute decision-maker) cannot be obtained, treatment may be given without consent.[29] In some jurisdictions, provincial legislation also specifically sets out further definition of "emergency" circumstances in which treatment without consent may be permitted. However, in line with the doctrine of informed consent, the Ontario Court of Appeal has ruled that treatment cannot be given if the patient (or their substitute decision-maker) is competent and refuses treatment, even in an emergency situation.[30]

The doctrine of informed consent applies equally to adults and to minors. However, two difficult questions arise with respect to making decisions regarding minors' medical treatment: *Who* is entitled to consent to, or refuse, treament? And *on what basis* are such decisions to be made?

Who Makes Medical Decisions for Minors?

As a general rule, parents are recognized as those with a legal right to make medical decisions on behalf of their children not capable of making these decisions for themselves. This is recognized both in the common law[31] and in provincial statutes that deal with consent to health care and substitute decision-making (unless a court has expressly appointed someone else under the provisions of such a statute).[32]

Parents also have legal obligations to ensure that their minor children receive required medical care; failing to do so may result in both civil liability for negligence and criminal liability for the offence of "failing to provide the necessaries of life."[33] In every jurisdiction, legislation also provides that child protection authorities may seek custody of a child in need of protection as a result of parental conduct or may seek a more limited authority, such as the authority to make medical treatment decisions on behalf of the child in place of the parent(s). Finally, courts have an inherent *parens patriae* jurisdiction to safeguard the well-being of "persons who are not able to take care of themselves."[34] Canadian courts have upheld such legislative or judicial interference with "parental rights" as being constitutionally permissible (see discussion below).[35]

However, both provincial legislation[36] and courts have recognized that some minors may in fact be capable of making their own medical decisions. In keeping with the respect for personal autonomy, the common law doctrine of the "mature minor" holds that a minor can legally consent or refuse a given medical treatment if they can understand and appreciate the nature and consequences of the procedure and their decision.[37] In the case of a mature minor, parental consent is not required, nor can the parent's refusal of a given treatment (legally) override the mature minor's decision. Nor, in the case of a mature minor, can any other person, such as child protection authorities or the court, supersede the minor's treatment decisions: "at common law a mature minor is 'able to take care of themselves' and may make decisions about medical treatment. In such a case, there is no room for a court to exercise its *parens patriae* jurisdiction."[38] In several of these cases, the mature minor's decision has been respected where their refusal of treatment was based on religious beliefs, such as teenage Jehovah's Witnesses refusing blood transfusions.[39] In another case, the minor refusing a transfusion on religious grounds was deemed to be incapable of making this decision.[40]

The "Best Interests of the Child"

In those cases where a minor is not "mature" enough to be capable of making their own medical decisions, it is the substitute decision-maker (such as a parent) who may give or refuse consent to any proposed treatment. Not surprisingly, the Supreme Court of Canada has clearly stated that such decisions must be based solely on the "best interests" of the child.[41] But in some cases, there is strong disagreement between health professionals and the decision-maker as to the appropriate treatment and what constitute the child's "best interests." As Gilmour points out in her review of the case law: "Difficulties arise not with the basic decision-making principle, which directs that the decision shall be made in the child's best interests, but rather, in determining whose understanding of 'best interests' shall prevail and the content to give that standard."[42]

In 1995, in *RB* v *Children's Aid Society of Metropolitan Toronto*,[43] the Supreme Court of Canada considered the question of whether Jehovah's Witness parents could refuse to permit their infant to receive needed blood transfusions. On short notice, the lower court had granted temporary wardship of the infant to child protection authorities; surgery (involving a transfusion) was performed; the court then terminated the wardship and returned the infant to her parents. The parents appealed these court decisions, arguing that their Charter rights to freedom of religion (s 2(a)) and to liberty (including parents' rights to choose medical treatment for their children) (s 7) had been infringed.

The Supreme Court recognized that parents' interest in caring for a child is an interest of "fundamental importance" and is protected by the right to liberty under section 7 of the Charter, but that this is not an "unconstrained freedom" and the state may intervene to protect a child if necessary. In this case, the Court found that while the parents' liberty had been infringed by overriding their right to refuse medical treatment for their child, this had been done "in accordance with the principles of fundamental justice," which included the protection of a child's right to life and to health.

The Court also accepted that the right of parents to raise their children according to their religious beliefs (including choosing or refusing medical treatments) is a fundamental aspect of freedom of religion, and that their Charter rights in this respect had been infringed. However, the Court concluded that this infringement was justified (under s 1 of the Charter): protecting children is a sufficiently important objective to warrant interfering with parents' rights; the process set out by the legislation in question was carefully crafted to ensure this infringement of parents' rights only where necessary to protect the child's health, and provided procedural protections for parents who wished to contest the attempt by child protection authorities to supersede parental authority over medical decisions.

While there have been other cases in which courts have considered the question of parental refusal to medically recommended treatment based on religious belief,[44] in other cases there is no such dimension to the disagreement over the appropriate treatment.[45] And, as Gilmour points out, in some cases there is not always a clear indication as to the "right" treatment:

> Where the benefits of treatment are not so obvious or unequivocal as they are with relatively simple procedures such as blood transfusions, or where the risks are significant, then decision-making becomes immeasurably more difficult both for the child's parents and for courts. Which reasons put forward by which families should be accepted and which rejected? And how to decide? Cases to date have emphasized one aspect of the determination – the medical assessment of the benefits and burdens of treatment and non-treatment, and medical practice.[46]

What the Supreme Court's decision in *RB*, and court decisions in other cases, confirm is that decisions about restricting parental control over their children's medical treatment are essentially questions to be decided on the basis of the facts of a particular case, as well as public policy considerations. As LaForest J wrote for the plurality in *RB*:

> State interference in order to balance the rights of parents and children will arise only in exceptional cases. In fact, we must accept that parents can, at times, make decisions contrary to their children's wishes – and rights – as long as they do not exceed the threshold dictated by public policy, in its broad conception.[47]

In the *RB* case, Gilmour summarizes the Court's reasoning as follows:

> Even with the dangers of transmitting infection now identified in the blood supply system, blood transfusions are a standard form of medical therapy, enjoy wide public acceptance, are not particularly invasive, do not generally cause major side effects, and are often necessary to preserve health and even life. Given its standard nature, the small degree of physical risk associated with a transfusion and the major risks anticipated from refusing it, and given strong medical opinion supporting the need for transfusion and wide

> societal acceptance of it as a form of treatment, the Court was not prepared to countenance the parental refusal. The life and physical health of the child clearly prevailed in the determination of the child's best interests.[48]

In another case, a court upheld a parent's refusal of chemotherapy for her child despite doctors' recommendations and an application by the hospital for court authorization to treat the child. In *Couture-Jacquet*, the Québec Court of Appeal based this decision on the small chance of success of the treatment, as well as the significant physical damage and suffering it would cause.[49]

Conclusion

What, then, are courts to do in circumstances where parents refuse to consent to having their minor child either tested for HIV infection where there are reasonable grounds to believe the child is at risk or, if the child is known to be HIV-positive, to follow recommended medical practice for treatment with antiretroviral therapy? There is no single, clear answer for parents, for health professionals, for child protection authorities, or for the courts. As a brief overview of the law indicates, and as is not surprising in the case of individual medical decisions, each case will need to be determined on the basis of its particular facts, informed by ethical and public policy considerations.

Certainly any medical decision, including those made by parents on behalf of HIV-positive children, must be an informed one based on available medical evidence. Similarly, that decision must be motivated by the best interests of the child. In the case of immature minors, the court's assessment of the child's interests will be informed primarily by medical evidence and expert opinion, and by the degree to which parental decisions divergent from that medical advice can be rationally defended. In such cases the courts are also less likely to accept that treatment decisions based on a parent's religious beliefs are to be determinative of the child's medical care. It remains to be seen whether courts will be more deferential to treatment decisions for an HIV-positive child based on an HIV-positive parent's own experiences with antiretroviral therapy and views about the appropriate use of such medications. It can also be expected that advances in treatment options will, of necessity, continue to influence the legal landscape when disagreements arise between parents and health professionals over the care of HIV-positive children.

– Richard Elliott

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[1] US: Court denies legal custody of child to breast-feeding mother with HIV. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(4): 12.

[2] Judge orders HIV-positive mother to treat child with AZT. *Oregon Live NewsFlash Online*, 15 December 1998; Oregon battles over AZT treatment for baby of HIV-positive mother. *Associated Press*, 1 February 1999.

[3] *In re Nikolas E*, 1998 WL 80328; see also: Maine Supreme Court affirms decision to let mother control child's AIDS treatment. *Lesbian/Gay Law Notes*, December 1998, <www.qrd.org/qrd/usa/legal/lgln/1998/12.98>; Boy is healthy without drug for HIV, mother says. *New York Times*, 20 September 1998, <www.nytimes.com>; Child's HIV drug withheld. [Australian] *HIV/AIDS Legal Link*, December 1998; 9(4); Court allows mother to refuse HIV treatment for her son. *USA Today*, 20 November 1998.

[4] *In re C*, [1999] TNLR No 652.

[5] Baby must have HIV test. *BBC News Online*, 3 September 1999, <www.bbc.co.uk>; Judge orders HIV test for baby. *Associated Press*, 3 September 1999; Girl must be tested for HIV, judge rules. *Reuters*, 3 September 1999; UK court rules infant should be tested for HIV over parents' objections. *Reuters*, 8 September 1999; H Branswell. Court asked to order HIV test for baby. *National Post*, 27 August 1999: A12

[6] C Dyer. Baby to be tested for HIV against parent's wishes. *British Medical Journal* 1999 (11 September); 319: 658.

[7] Baby must have HIV test. *BBC News Online*, 3 September 1999, <www.bbc.co.uk>.

[8] Parents "flee" over baby's HIV test. *BBC News Online*, 18 September 1999, <www.bbc.co.uk>; UK couple flees after HIV test ordered. *Fox News Online*, 18 September 1999, via CDC HIV/STD/TB Prevention News Update, 20 September 1999.

[9] HIV mother told to test baby. *BBC News Online*, 21 September 1999, <www.bbc.co.uk>.

[10] Baby in HIV court struggle. *BBC News Online*, 23 August 1999, <www.bbc.co.uk>.

[11] National AIDS Trust. News Release: National AIDS Trust statement on HIV test High Court case. 23 July 1999, <www.nat.org.uk>; HIV test ruling: the reaction. *BBC News Online*, 3 September 1999, <www.bbc.co.uk>.

[12] National AIDS Trust. News Release: National AIDS Trust statement on HIV test High Court ruling, 3 September 1999, <www.nat.org.uk>.

[13] Ibid.

[14] National AIDS Trust. News Release: National AIDS Trust calls for support to ante-natal testing campaign, 13 August 1999, <www.nat.org.uk>.

[15] The Terrence Higgins Trust. THT response to testing court decision, 3 September 1999, <www.tht.org.uk>.

[16] George House Trust. Media release: Courts take away mother's right to choose. 3 September 1999, <www.georgehousetrust.org.uk>; Children and HIV tests: head to head. *BBC News Online*, 26 August 1999, <www.bbc.co.uk>; HIV testing ruling: the reaction. *BBC News Online*, 3 September 1999, <www.bbc.co.uk>.

[17] *Brassard* v *Youth Protection Services et al*, Québec Superior Court, District of Montréal, Court File No 500-05-052175-997.

[18] AIDS virus harmless: group. *Canadian Press Wire*, 18 August 1999; I Peritz. Mother fights to block son's HIV drug therapy. *Globe and Mail*, 18 August 1999: A1-A2; A Derfel. Mother seeks to deny son HIV drugs. [Montréal] *Gazette*, 19 August 1999: A3; Rejecting HIV treatment. *Maclean's*, 30 August 1999: 23; M Kennedy. Opposed to AIDS drugs, mothers go underground. *Ottawa Citizen*, 7 September 1999.

[19] Woman drops suit over HIV drugs. [Montréal] *Gazette*, 23 October 1999: A6; Woman abandons suit to keep son off HIV drugs. *Globe and Mail*, 23 October 1999: A5.

[20] M Ko. HIV-positive mom in hiding, fearing forced treatment of kids. *Globe and Mail*, 25 October 1999: A7.

[21] B Pilon. HIV mom flees to Alberta. *Edmonton Sun*, 26 October 1999: 5; HIV mom in Alberta. *Calgary Sun*, 26 October 1999: 8; J Williams. Children "wouldn't face mandatory tests." *Calgary Herald*, 26 October 1999: A11.

[22] For an excellent discussion of minors and medical treatment in Canadian law, see J Gilmour. Minors. In: J Downie, T Caulfied (eds). *Canadian Health Law and Policy*. Markham: Butterworths Canada Ltd, 1999, at 179-216.

[23] *Hopp* v *Lepp*, [1980] 2 SCR 192; *Reibl* v *Hughes*, [1980] 2 SCR 880.

HIV/AIDS IN CANADIAN COURTS

This section of the *Newsletter* presents a summary of miscellaneous Canadian court cases reported in June to October 1999 relating to HIV/AIDS. A review of 1998 and early 1999 cases was included in previous issues of the *Newsletter*, and subsequent cases will be summarized in future issues. A search of Canadian electronic legal databases yielded several cases reported in June to October 1999 in which reference was made to HIV/AIDS. However, only those cases that dealt with HIV/AIDS or HIV/AIDS-related litigation in any substantive way have been summarized here; cases dealing with minor procedural matters related to litigation have been excluded. (Readers aware of any unreported cases that would be of interest to the Network and *Newsletter* readers are asked to draw these to the Network's attention.) The cases below deal with discrimination by insurance companies, assisted suicide, immigration issues, criminal harassment and libel, and allegations of HIV infection raised in the criminal trial of the owner of a Toronto escort agency. Criminal cases and cases relating to HIV/AIDS in prisons (both in Canada and other jurisdictions) are summarized elsewhere in this issue.

BC Human Rights Tribunal Rules on Discrimination by London Life

In June 1999, a British Columbia human rights tribunal ruled that London Life Insurance Company had violated the province's *Human Rights Act*[1] in 1994 by refusing to sell life insurance (on his own life) to an HIV-negative man on the basis that his wife is HIV-positive.

In *J* v *London Life Insurance Co*,[2] the tribunal heard that other insurance companies had also refused to insure him. In his application to London Life, J disclosed the fact that his wife was HIV-positive (since 1985), that he himself had repeatedly tested negative, and that he and his wife were taking proper precautions to prevent transmission. J tested HIV-negative

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[24] For example, see: *Rodriguez* v *BC (AG)*, [1993] 3 SCR 519; *Nancy B* v *Hôtel Dieu de Québec* (1992), 86 DLR (4th) 385 (Que SC); *Walker (Litigation Guardian of)* v *Region 2 Hospital Corp* (1994), 116 DLR (4th) 476, [1994] NBJ No 242 (QL) (NBCA); *Re K(LD)* (1985), 48 RFL (2d) 164 (Ont Prov Ct).

[25] *Malette* v *Shulman* (1990), 37 OAC 281 (CA) at 285.

[26] *Fleming* v *Reid*, (1991) 82 DLR (4th) 298 (CA) at 309-310.

[27] *Ciarlariello* v *Schacter*, [1993] 2 SCR 119, cited in *Walker*, supra, note 24.

[28] *Fleming*, supra, note 26 at 312-313.

[29] *Walker*, supra, note 24; *Malette*, supra, note 25; *Marshall* v *Curry*, [1933] 3 DLR 260 (NSTD).

[30] *Malette*, supra, note 25.

[31] *RB* v *Children's Aid Society of Metropoliton Toronto*, [1995] 1 SCR 315.

[32] Eg, *Health Care Consent Act, 1996*, SO 1996, c 2 (Sch A), s 20.

[33] *Criminal Code*, RSC 1985, c C-46, s 215.

[34] *Beson* v *Director of Child Welfare (Nfld)*, [1982] 2 SCR 716; *E* v *Eve*, [1986] 2 SCR 388; *Fleming*, supra, note 26 at 315-316; *Walker*, supra, note 24 at QL para 29; *Ney* v *Canada (AG)* (1993), 79 BCLR (2d) 47 (SC); *Kennett Estate* v *Manitoba (AG)* (1998), 129 Man R (2d) 244 (CA).

[35] *RB* v *Children's Aid Society of Metropolitan Toronto*, supra, note 31; *Alberta (Director of Child Welfare)* v *Harrison*, infra, note 44.

[36] Eg, *Medical Consent of Minors Act*, SNB 1976, c M-6.1.

[37] *Walker*, supra, note 23; *Johnston* v *Wellesley Hospital* (1970), 17 DLR (3d) 139 (HC); *Ney*, supra, note 33; *Re AY* (1993), 111 Nfld & PEIR 91; *C(JS)* v *Wren*, [1987] 2 WWR 669 (Alta CA); *Re K(LD)*, supra, note 23.

[38] *Walker*, supra, note 24 at QL para 26.

[39] *Walker*, supra, note 24; *Re AY*, supra, note 37; *Re K(LD)*, supra, note 24.

[40] *H(T)* v *Children's Aid Society of Metropolitan Toronto* (1996), 138 DLR (4th) 144 (Ont Gen Div).

[41] *E* v *Eve*, supra, note 34.

[42] Gilmour, supra , note 22 at 200.

[43] *RB*, supra, note 31; 78 OAC 1.

[44] *Alberta (Director of Child Welfare*) v *Harrison*, [1996] AJ No 501 (Alta QB).

[45] *Re Superintendent of Family & Child Service and Dawson* (1983), 145 DLR (3d) 610 (BCSC); *New Brunswick (Minister of Health & Community Services)* (1990), 70 DLR (4th) 568 (NBQB); *Re Goyette: Centre des Services Sociaux du Montréal*, [1983] C 429 (Que SC); *Children's Aid Society of Peel (Region)* v *B(C)*, unreported, 9 February 1988, Karswick PCJ, (988), ACWS (3d) 425 (Ont Prov Ct), cited in Gilmour, supra, note 22 at 199; *Saskatchewan (Minister of Social Services)* v *P(F)* (1990), 69 DLR (4th) 134 (Sask Prov Ct).

[46] Gilmour, supra, note 22 at 201.

[47] *RB*, supra, note 31 at 373.

[48] Gilmour, supra, note 22 at 198.

[49] *Couture-Jacquet* v *Montreal Children's Hospital* (1986), 28 DLR (4th) 22 (Que CA).

during the medical exam required for his application to London Life.

Two adjusters and two physicians from London Life stated that the company could not insure J because he

> is in a high-risk situation for contracting the AIDS virus. His current status is HIV-negative but because of the inherent risk of developing the virus, this places him in an uninsurable category at this time.

London Life's vice-president and chief medical director

> stated that J was not denied insurance because his wife was HIV-positive, but agreed that if his spouse was HIV-negative, he would have obtained the life insurance. [He] testified that the reason J was uninsurable was that he was having or continuing to have sexual relations with an HIV-positive individual.[3]

He further testified that, to his knowledge, there were no industry studies regarding transmission rates of HIV in 1994, and that in making a decision to deny insurance to people in J's situation, London Life had not undertaken any actuarial studies to determine the risk of HIV infection. A few years later, London Life changed its practice as a result of new drug therapies available to HIV-positive people, that reduced the risk of transmission. In 1997, London Life began to issue life insurance policies to individuals whose partners were HIV-positive, and invited J to re-apply for life insurance. He declined, as he had successfully obtained insurance elsewhere in 1995, after London Life had turned him down.

The tribunal found that London Life's blanket policy of excluding coverage for spouses of HIV-positive individuals amounted to discrimination on the basis of marital status.

Citing earlier case law, the tribunal concluded that the prohibition against discrimination on the basis of "marital status" extends to protect individuals from discrimination by reason of their marital relationship with a particular person. The tribunal found that London Life's blanket policy of excluding coverage for spouses of HIV-positive individuals amounted to discrimination on the basis of marital status.

The tribunal further concluded that London Life had discriminated against J on the prohibited ground of physical disability, which also prohibits discrimination on the basis of a perceived disability. In an earlier decision that extensively reviewed Canadian and US case law, the BC Human Rights Council had concluded that protection against disability discrimination will extend to any person who falls within a group of persons considered or perceived to be at high risk of contracting HIV.[4] In this case, the tribunal found that London Life had denied J coverage because of its conclusion that he was at increased risk of HIV infection on the basis of sexual relations with his wife, which amounts to prohibited discrimination.

Finally, the tribunal considered whether London Life could establish any "*bona fide* and reasonable justification" for denying J life insurance. In *Zurich Insurance Co* v *Ontario*,[5] the Supreme Court of Canada considered the application of human rights statutes to insurance practices. The Court ruled that a discriminatory practice is reasonable if it meets two criteria: (a) it is based on a sound and accepted insurance practice [ie, adopted for the purpose of achieving the legitimate business objective of charging premiums that are commensurate with risk], and (b) there is no practical alternative [having regard to all the facts of the case].

In J's case, the tribunal agreed that this analysis was equally applicable to the sale of both group and individual life insurance (although it may be relevant to take into account the differences between group and individual insurance in assessing whether a given practice is, in fact, designed to establish premiums commensurate with risk). London Life argued that the fact that three other companies had also refused to insure J confirm that this was accepted industry practice based on J's risk category. However, the tribunal agreed with J's argument that London Life could not defend its policy as sound insurance practice: in the absence of actuarial and statistical evidence establishing the risk of insuring him, the insurance company has produced only anecdotal evidence and its refusal to provide coverage is based on its inability to assess the risk.

The tribunal therefore ordered London Life to pay J a sum of $3000 for injury to his dignity, feelings, and self-respect. It also ordered London Life to refrain in future from discriminating against people whose spouses are HIV-positive.

– Richard Elliott

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[1] RSBC 1996, c 210.

[2] [1999] BCHRTD No 35 (QL).

[3] Ibid at para 12.

[4] *Biggs* v *Hudson* (1988), 9 CHRR D/5391.

[5] [1992] 2 SCR 321.

AIDS Organizations Denied Leave to Intervene in Insurance Case

In October 1999, the BC Court of Appeal denied the request of the Canadian AIDS Society (CAS) and the BC Persons with AIDS Society (BCPWA) to intervene in the appellate hearing of a case raising questions about the responsibilities of employers and employees to preserve entitlement to life insurance coverage.[1] In this case, the issue of the mental capacity of a man with AIDS-related dementia was a key issue.

In September 1997, a BC trial court had dismissed a claim by the estate of a BC man who died of AIDS against his former employer for damages arising out of his termination. The trial judge had found that the employer, BC Rail, had dismissed the employee without cause.[2] One aspect of the damages claimed by the employee was the loss of his employment benefits, including life insurance coverage. The employer, however, argued that the employee had failed to mitigate his losses arising from the dismissal, in that he had not sought to preserve his life insurance coverage by applying to convert his group policy into an individual one after he was terminated. As a general rule, anyone suing for damages for a breach of contract (such as an employment contract) is under an obligation to take reasonable steps to lessen their losses caused by the breach, and cannot be compensated for any losses that they could have avoided by acting reasonably.

According to the terms of the policy, the employee had a certain period of time (roughly two months) following his termination to apply to convert his group insurance coverage to individual coverage. The trial judge found as fact that the employee, who was diagnosed with AIDS-related dementia, had the mental capacity to take the necessary steps to convert his policy, up until approximately two weeks before his death. Before the point at which he was deemed to have become mentally incompetent, he had not yet taken these steps. The trial judge concluded from this that the employee had "failed to mitigate" the loss of his insurance coverage and so could not recover this from the employer who had wrongfully dismissed him.

On appeal, the employee's estate argued that this conclusion was legally wrong in light of the fact that the employee had lost his mental capacity before the end of the conversion period. The employee's estate also argued that the trial judge erred in law in holding that the employee continued to owe a duty to the employer to mitigate his losses by applying to convert his insurance policies, even though the employer actually knew of his physical and emotional impairment during this conversion period. The final ground of appeal was that the judge had erred in holding that the employer had discharged its burden of proving the employer's failure to mitigate his losses, because the employer had not shown that the insurance company would likely have approved the employee's application to convert his policies.

CAS and BCPWA sought leave to intervene to make submissions regarding the social and medical context in which AIDS dementia presents itself, including the argument that it is a difficult condition to diagnose and its impact is often misunderstood or minimized. They also wanted to argue that, because AIDS renders a person uninsurable, preserving insurance coverage would have been the deceased employee's only rational choice. Therefore, they submitted, the Court should have relieved against the strict application of the law to the mentally infirm, including those with AIDS-related dementia.

However, the BC Court of Appeal refused leave to intervene, saying the organizations proposed "simply a disguised attack on the learned judge's finding of fact ... as to the mental capacity" of the employee at the relevant time. In the motions judge's view, the court should not permit these strangers "to intermeddle on a question of material fact," and that the organizations were free to put any new legal theory of the case to the lawyer for the employee's estate.

The case was scheduled to be heard in the BC Court of Appeal at the end of October 1999.

– Richard Elliott

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[1] *A. Estate* v *BC Rail Ltd*, [1999] BCJ No 2243 (CA) (QL).

[2] *EE* v *ER*, [1997] BCJ No 1966 (SC) (QL).

No Removal of HIV-Positive Man for Marijuana Conviction

In June 1999, the Immigration Appeal Division of the Immigration and Refugee Board dismissed a motion by the federal government to order the removal from Canada of an HIV-positive (and hepatitis C–positive) man for a drug offence.[1]

The man had pleaded guilty to one count of possessing marijuana for the purposes of trafficking (and failing to appear in court on two occasions relating to this offence).

The panel noted that this was a fairly minor offence (only 1.4 grams of marijuana was involved). Furthermore, his physician had recommended the use of marijuana to stimulate his appetite, as his antiretroviral combination therapy produced extreme nausea. While usually a customer of the Compassionate Club for his marijuana, on this particular occasion he had run out of his supply and purchased some on the street. He had the misfortune of being caught in an undercover police operation and pleaded guilty to avoid imprisonment. However, he spent 45 days in prison (in medical segregation), during which time he had difficulty accessing his medications.

The panel concluded that this was not a serious offence in the circumstances, and that it did "not consider his use of small amounts of marijuana to be illegal" or contrary to the terms and conditions upon which an earlier order to remove him from Canada had been stayed. The panel therefore continued to stay the execution of the removal order against him.

– Glen Bugg

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[1] *Hutchinson* v *Canada (Minister of Citizenship and Immigration)*, [1999] IADD No 1031 (QL).

Criminalization of Assisted Suicide Challenged

In September 1999, Jim Wakeford, a Toronto man with HIV/AIDS, launched a civil action against the Attorney General of Canada, challenging the constitutionality of sections of the *Criminal Code*[1] that criminalize assisted suicide.

Section 241 of the Code states that:

> Every one who (a) counsels a person to commit suicide, or (b) aids or abets a person to commit suicide, whether suicide ensues or not, is guilty of an indictable offence and liable to imprisonment for a term not exceeding fourteen years.

Furthermore, section 14 of the Code states that:

> No person is entitled to consent to have death inflicted on him, and such consent does not affect the criminal responsibility of any person by whom death may be inflicted on the person by whom consent is given.

In his statement of claim,[2] Wakeford states that he has been advised by his physicians that he likely has another two to three years to live, and that he does not wish to experience the "devastation and loss of dignity and autonomy that accompanies the final stages of death by AIDS," nor does he wish "to impose the mental suffering on his friends and family that will accompany his death by AIDS." Rather, Wakeford states that he "wishes to end his life by his own act, with dignity, with medical assistance to ensure that his suicide is as painless as possible, effective, and will not be interrupted or prevented by public authorities."

Wakeford argues that the *Criminal Code* provisions prevent him from obtaining assistance in committing suicide from a competent and licensed medical practitioner, thereby imposing a disproportionate burden on him as a person with HIV/AIDS. He therefore seeks a declaration from the court that the provisions of the Code discriminate against him on the basis of physical disability, contrary to the equality provisions of the *Canadian Charter of Rights and Freedoms* (s 15). He also seeks a court order granting him and any licensed Ontario medical doctor(s) selected by him a constitutional exemption from these sections of the Code. In the alternative, he seeks a court order striking out these sections as unconstitutional.

Wakeford's claim distinguishes his case from that eventually brought before the Supreme Court of Canada in 1992 by Sue Rodriguez, a British Columbia woman with amyotrophic lateral sclerosis (ALS). In *Rodriguez*,[3] the Supreme Court decided (by a 4-3 majority) that, while these sections of the *Criminal Code* do indeed violate the equality rights guaranteed by s 15 of the Charter, nonetheless this breach of constitutional rights was a "reasonable limit" that was "demonstrably justified in a free and democratic society" (under s 1 of the Charter).

Wakeford argues that his case is different for a number of reasons. First, because he is seeking only a personal constitutional exemption from these *Criminal Code* sections, this

> will not open the door to a flood of unsupervised or uncontrolled suicides that could lead to the abuses that concerned the [majority of the] Supreme Court of Canada [in *Rodriguez*].... Rather, any person seeking assisted suicide following a positive decision in this case would have to obtain an order from the court, on notice to the Attorney General."

Second, Wakeford argues, Rodriguez sought permission for another person to inflict death upon her, since she was unable to do this herself. Wakeford argues that he "seeks assistance, but intends to both make the decision to die, and to inflict death upon himself."

Third, Wakeford argues that new developments in Canada have changed the legal landscape. In the *Rodriguez* case, the Supreme Court found that the federal government could justify the breach of Sue Rodriguez' equality rights. Since that decision, the issue of assisted suicide has received government scrutiny, resulting in a Senate report. Wakeford wrote to Prime Minister Jean Chrétien requesting assisted suicide. The Prime Minister's response was that the Senate Committee examining the issue had concluded there was "insufficient social consensus" to warrant changing the criminal law. Wakeford now argues that this not a constitutionally acceptable basis for justifying the discrimination embodied in the *Criminal Code* prohibitions on assisted suicide: "majoritarian sentiment is never a basis for justifying discrimination." Wakeford argues that Canada has failed to take any steps to strike the necessary balance in the law so as to minimally impair his equality rights in legislating with respect to assisted suicide.

– Richard Elliott

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[1] RSC 1985, c C-46, as amended.

[2] Statement of Claim, *Wakeford* v *Attorney General of Canada*, Court file no 99-CV-175987, Ontario Superior Court of Justice.

[3] [1993] 3 SCR 519.

No Duty to Preserve Benefits for Employee with Dementia

In August 1999, an Ontario trial court granted an employer's motion for a summary judgment dismissing a claim against it by the estate of a former employee who died of AIDS-related illness.

In *Bueckert Estate* v *IBM Canada Ltd*,[1] the employee's estate sued his former employer to obtain disability benefits allegedly owed. The employee was known by some co-workers as having hemophilia, but he did not tell anyone at the workplace that he was HIV-positive. He had learned of his infection in 1986 and was diagnosed with AIDS in 1988. Several months before his 1992 resignation from IBM, a co-worker observed him demonstrating some uncharacteristic behaviour (mismatched shoes, not shaving, forgetting his wallet). While he experienced symptoms such as oral candidiasis, pneumonia, and oral hairy leukoplakia in the months preceding his resignation, he did not mention these to anyone at the workplace. Until his resignation, he did not miss any work due to illness or disability. He resigned to take a position with another company, a position that included full disability benefits.

Bueckert's estate argued that medical evidence established that, at the time of his resignation, he was disabled by AIDS-related dementia, which affected his ability to make a rational decision regarding resignation. This, together with his conduct in the months prior to resigning, imposed a duty on IBM as his employer to ensure that he made an informed decision before forgoing the long-term disability benefits to which he would be entitled. The estate therefore alleged the employer was liable for breach of the employment contract and/or in tort for negligence because it did not discharge its duty of care toward Bueckert.

In response, IBM argued that there was no breach of contract on its part as a result of Bueckert's resignation to move to another employer. It also argued that there was no duty of care to Bueckert, or any breach of such a duty, as there was no suggestion of his disability to IBM, which was therefore not in a position where it knew or ought to have known of his potential disability.

The court agreed with IBM. It distinguished Bueckert's claim from two earlier cases in which employers knew or ought to have known of an employee's disabling mental illness and were therefore negligent in not taking steps to assist the employee in accessing benefits.[2] In Bueckert's case, the court concluded that there was nothing "which could attribute to the employer any knowledge or even hint that their employee was suffering a disabling condition. In such circumstances it does not seem to me that there is a duty on the employer of the kind that is referred to in the above-noted cases." Citing other cases, the court stated:

> Put at its highest, [Bueckert's] articulation of the duty is that IBM should not have permitted Bueckert to resign. This is a much broader duty than any of the decided cases.... [T]here was no duty on an employer to provide disability benefits where there was no complaint by the employee which could give rise to benefits.[3]

– Richard Elliott

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[1] [1999] OJ No 3179 (Ont SCJ) (QL).

[2] *Tarailo v Allied Chemical Canada Ltd* (1989), 68 OR (2d) 288 (Ont Ct Gen Div); *Spring v Saley* (1998) ICCLI (3d) 167 (Ont Ct Gen Div).

[3] *Beaird v Westinghouse Canada Inc* (1999), 43 OR (3d) 581 (CA); *O'Connell v Canadian National Institute for the Blind*, [1998] OJ No 3430 (Gen Div) (QL).

Appeal Board Denies Public Health Insurance Coverage to Immigrants on Minister's Permits

In a decision released in August 1999, the Health Services Appeal Board in Ontario upheld the decision to deny provincial health coverage to an HIV-positive woman who had been denied permanent resident status on the basis of "medical inadmissibility" but was living in Canada on an Immigration Minister's Permit issued on "humanitarian and compassionate grounds."[1]

Background

SP is a French citizen. Her husband and two children are Canadian citizens. She tested HIV-positive in November 1991. In March 1993, she entered Canada as a visitor, which status was valid until September 1994. She was also issued both an employment authorization and a student authorization to enter Canada, both valid until November 1994. As a result, she was enrolled by the Ontario Health Insurance Plan (OHIP) for medical coverage as a foreign student.

Shortly after SP entered the country, her husband applied to sponsor her for landing as a permanent resident, undertaking to sponsor her for 10 years. As a result of her HIV-positive status, two medical officers of Immigration Canada deemed her "medically inadmissible" to Canada under section 19 of the *Immigration Act*.[2] Immigration Canada deems an applicant to be medically inadmissible if it is estimated that, for five or more years, the applicant's estimated health-care costs exceed five times the average baseline cost of health per person (currently pegged at $2500 per year). SP's application for permanent residence was denied on this basis. She did not appeal this decision.

In April 1994, SP was advised by the General Manager of OHIP that her coverage as a foreign student would end in three months as a result of changes to the legislation governing OHIP. Previously, the definition of "resident" under Ontario's *Health Insurance Act*[3] included any individual who was legally entitled to remain in Ontario, and was ordinarily present and made their home in the province. In April 1994, the Ontario government introduced amendments to the Act and accompanying regulation.[4] These amendments disentitled many foreign students, foreign workers, Convention refugee claimants, and applicants for landing as permanent residents from provincial health insurance coverage. Under the new statutory regime, OHIP coverage is restricted to Canadian citizens, landed immigrants, and individuals holding a specific kind of Minister's Permit (those who have applied for landed immigrant status from within

Canada and have been permitted to remain within the country because only routine processing steps remain in considering their application).

In July 1995, Immigration Canada reviewed the circumstances of SP's case, including indications from her physicians that she was asymptomatic, that her condition was stable, and that they anticipated she would remain healthy for about 10 years. Immigration Canada issued a discretionary Minister's Permit allowing her to remain in Canada until July 1997 on "humanitarian and compassionate grounds." The kind of Minister's Permit issued indicates that SP's application for landing as a "family class" applicant was refused on the basis of medical inadmissibility. She was also issued an employment authorization valid until July 1997.

SP re-applied for her provincial health coverage that was terminated in June 1994, providing OHIP with a copy of her Minister's Permit. In 1996, she was denied OHIP coverage on the basis that her Minister's Permit was not the kind of permit that makes her eligible for OHIP coverage, as a result of the Ontario government's 1994 amendments to the *Health Insurance Act*. Represented by counsel from the HIV & AIDS Legal Clinic (Ontario), she appealed this decision to the Health Services Appeal Board. The hearing was held in July 1997; the Board released its decision in August 1999.

Legal Issues

Evidence presented to the Board indicated that managing HIV disease is complex and expensive, involving complicated regimens of aggressive antiretroviral therapies and requiring regular monitoring tests. SP's family physician testified that SP was not currently accessing such therapy because of concern that she would not be able to access appropriate monitoring of the medications' effects because she was not eligible for OHIP, and that were SP to be covered by OHIP she would have appropriate referrals from the community health centre to deal with psychiatric care issues and other medical concerns.

SP did not argue that there was no access to HIV-related treatment in Ontario for a person without OHIP coverage, but that this coverage was inadequate because the provincial health-care regime and its restrictive financing constrains the aggressive treatment and monitoring options required to control HIV disease for someone without OHIP coverage. SP argued that this state of affairs is unconstitutional because it breaches two sections of the Charter: the equality rights provision (s 15) and the rights to life and security of the person (s 7).

Equality rights (section 15)

SP argued that the OHIP regulation discriminates on the basis of physical disability, contrary to the equality rights provisions of the Charter (s 15). Other family class–sponsored immigrants in circumstances otherwise identical to SP's, but who are HIV-negative, are routinely granted landing and are, as a result, routinely eligible for OHIP. SP argued that the regulation withholds OHIP eligibility from a group of people on the basis of their combined physical disability (HIV infection) and citizenship or national origin (sponsored family-class immigrants). Section 15 of the Charter prohibits discrimination on these grounds.

However, the Board concluded that SP's "ineligibility for OHIP flows from a determination by Immigration Canada that she is medically inadmissible to Canada, and the subsequent refusal of her application for permanent residence."[5] The Board therefore said that any discrimination against SP results from federal government immigration policies, not from Ontario's regulation; the Board asserted that this was beyond the Board's jurisdiction.

The Board also noted that other persons without any disability, or with other medical disabilities such as cancer, may also be refused landing by the federal government on the basis of medical inadmissibility, so someone who is not HIV-positive may also be denied OHIP coverage as a result of being refused landing. Similarly, the Board noted that not all HIV-positive persons are excluded from OHIP coverage, because Canadian citizens or permanent residents who move to Ontario from other provinces are eligible for OHIP. The Board therefore concluded: "Given that persons with differing disabilities may be deemed inadmissible to Canada, and therefore not eligible for OHIP, and the fact that other persons with HIV may be eligible for OHIP, we cannot conclude that the appellant's rights under section 15 are being infringed *simply* because of her HIV status."[6] [emphasis added] The Board did not address SP's argument that the legislation discriminates on the basis of the *combination* of her HIV-positive status and her citizenship or national origin.

Rights to life and security of the person (section 7)

SP argued that denying access to appropriate medical care significantly threatens her bodily security, to such an extent that it may cost her her life, and that this amounted to an infringement of her rights to life and to security of the person under the Charter (s 7). However, the Board noted that SP was receiving publicly funded medical care through her local "community health centre," some prescription drug coverage as a social assistance recipient, emergency medical treatment at hospitals if necessary, and other publicly funded community services for people with HIV/AIDS. The Board also concluded from the evidence that the decision by SP's community health centre not to fund certain tests or provide payment for specialist care "appears to be a clinical (or financial) decision arrived at by her medical consultants, rather than a governmental action or decision of the type which would attract the protection of section 7."[7]

Conclusion

The Board rejected the argument that the term "permanent resident" should be given a "plain language" meaning of someone who resides permanently in Ontario, without regard for their legal immigration status in Canada: "there appears to be an inherent contradiction in finding that someone who is deemed inadmissible into Canada could be a 'permanent resident' of Ontario."[8] In the Board's view, such a broad interpretation would "open the floodgates" to OHIP eligibility and was not intended by the legislature, and that the "line drawing" exercise of the legislature in allocating scarce health-care resources does not infringe on SP's equality rights or her security of the person.

– *Richard Elliott*

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[1] *SP* v *Ontario Health Insurance Plan*, 19 August 1999, No 5399E (Ont Health Services Appeal Board), on file.

[2] RSC 1985, c I-2, s 19(1)(a)(ii). For a summary of Canadian law and policy regarding immigration of persons living with HIV/AIDS, see R Jürgens. *HIV Testing and Confidentiality: Final Report*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998, at 196-207.

[3] RSO 1990, c H.6, as amended.

[4] RRO 1990, Reg 552.

[5] *SP*, supra, note 1 at 36.

[6] Ibid at 37.

[7] Ibid at 40.

[8] Ibid at 41.

Newfoundland Man Pleads Guilty to Criminal Harassment

In May 1999, a Newfoundland trial court sentenced a 30-year-old man after he pleaded guilty to one count of criminal harassment for posting public notices that his ex-girlfriend was HIV-positive and had unprotected sex without disclosing this fact.[1]

The accused, Paul Perrier, and the complainant broke up after a three-year relationship. After a year apart, during which time they both had sexual relationships with other people, they resumed their relationship. During the breakup period, the complainant had sex with a former boyfriend. She had once commented to Perrier that she would not be surprised if that former boyfriend "had AIDS." After resuming her relationship with Perrier, which included unprotected sex over several months, she informed him of having had sex with that former boyfriend during the breakup. Roughly two years after the relationship had resumed, the complainant finally broke it off.

Perrier refused to accept this, following her vehicle the evening of the breakup and subsequently writing "obscene and vulgar" letters demanding she return rings, and threatening he would release a pornographic video of her. One of his letters also indicated that she should be thankful he had tested HIV-negative. However, he subsequently published electronic messages on a website, and put up posters around her community. These posters contained obscene allegations about the complainant's sexual history, and stated she was a "lying slut," had slept with a man who had AIDS, was HIV-positive herself, and did not tell this to her boyfriend until after sex. The poster included the complainant's face superimposed on a naked female body. He subsequently posted notices at her workplace, alleging she was HIV-positive and having unprotected sex, and urging sexual contacts to get tested, and then posted the same content in an email to her former school. When informed by the police of the complaint against him, he told them he wanted the complainant charged with "trying to spread the AIDS virus," and that he wished to be charged himself for publishing the obscene material to ensure the complainant would have to testify in court.

In exchange for his guilty plea to one charge of criminal harassment, the prosecution stayed an additional count of this offence and five charges of defamatory libel (a rare criminal charge). The trial judge took into account the sentencing principles set out in the *Criminal Code*, including the principle that all available sanctions other than imprisonment that are reasonable in the circumstances should be considered. He also considered aggravating factors such as: Perrier's prior convictions; the fact that the activity continued for several months; the widespread distribution and extremely offensive and humiliating nature of the allegations about the complainant; and his continued belief that he was justified in such drastic action. He also considered as mitigating factors: the fact that Perrier entered a guilty plea; his "emotional turmoil" resulting from being told by the complainant, after unprotected sex, that she had had sex with a person she believed had AIDS. The complainant testified as to the physical and psychological harm she had suffered as a result of Perrier's actions.

The terms of Perrier's conditional sentence include standard terms such as being of good behaviour and reporting to a probation officer as required, as well as avoiding all contact with the complainant or people at her workplace, and remaining in his residence for the 15 months of his sentence except for specific and limited exceptions (including employment or schooling). Any breach of the terms of the conditional sentence may result in Perrier being imprisoned for the unexpired portion of the sentence.

– Richard Elliott

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[1] *R v Perrier*, [1999] NJ No 190 (SCTD).

Allegations of HIV Infection Raised in Criminal Trial of Escort Agency Owner

At the beginning of October 1999, a Toronto man who owned an escort agency went to trial in the Ontario Superior Court of Justice on numerous charges of living off the avails of prostitution and procuring for the purpose of prostitution. On the first day of trial, the prosecutor indicated he would be introducing evidence suggesting that three of the women who worked as escorts for Mark Lucacko's agency may be HIV-positive.[1]

As reported, this evidence consisted of some handwritten notations on the back of index cards that recorded the escorts' age, physical details, and sexual acts they were or were not willing to provide to customers. While not relevant to the prostitution-related charges before the court, daily media coverage of the trial focused primarily on this allegation. (Within two weeks, some media reports asserted as fact that the women were HIV-positive, even though this had not been proved.) The trial judge eventually ordered that the identities of the clients, escorts, and any personal information disclosing their names be blanked out from any evidence filed with the court, and ordered a publication ban on any such information.[2]

A week later, the city's public health department appeared before the trial judge requesting that he provide public health officials with the names of the three escorts alleged to be HIV-positive and the names of their clients. The department argued that their mandate included following up on all reported cases of HIV, to ensure those who are exposed receive appropriate counseling and treatment, and to discharge the department's obligation to conduct contact tracing so as to notify all possibly infected sexual partners of these three escorts.[3] However, referring to the provisions of the *Criminal Code* regarding publication bans, Keenan J dismissed the department's request, ruling that it was in the wrong forum. He suggested the department explore other options if they wished to obtain the names. He also noted the information had been in the possession of police for over 2½ years before the trial.[4] The public health department subsequently issued an order, under the provincial *Health Protection and Promotion Act*, to police to provide them with the list of clients.[5]

– Richard Elliot

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[1] Eg, see: J Gadd. Escort agency knowingly used HIV-positive women, court hears. *Globe & Mail*, 6 October 1999: A11.

[2] Eg, see: J Gadd. Arguments to be heard on escorts' client list. *Globe & Mail*, 6 October 1999: A15; A Teplitsky, N Pron. Escort client list may become public. *Toronto Star*, 7 October 1999; Names and addresses will not be revealed, judge rules. *Canadian Press Wire*, 7 October 1999; N Pron, A Teplitsky. Judge refuses to name names in escort case. *Toronto Star*, 8 October 1999.

[3] Health officials want infected escorts named. *Canadian Press Wire*, 14 October 1999; N Pron, R DiManno. Give us escort list: Health office. *Toronto Star*, 14 October 1999; J Gadd. City asks court to name escorts feared infected. *Globe & Mail*, 14 October 1999: A13; C Eby. Health officials want client list of escort service. *National Post*, 14 October 1999: A23.

[4] G Abbate. Health officials denied access to names of infected prostitutes. *Globe & Mail*, 15 October 1999: A1; K Gillespie. Health board may still get escort list. Lawyers examine "other means" to get names. *Toronto Star*, 15 October 1999.

[5] B Honywill. City gets "john" list. *Toronto Sun*, 22 October 1999: 10; P Moloney. Health department gets escort client list. *Toronto Star*, 23 October 1999: B5.

PREGNANCY AND HIV/AIDS

A Different Kind of Risk? – Pregnant Women's Experience of HIV Testing in Pregnancy

This paper describes some emerging themes developed from conversations with pregnant women participating in a pilot study in Ottawa and Montréal. These initial findings will inform a national study that will address the issue of HIV screening in pregnancy from the perspectives of the women themselves. Through an iterative series of conversations with each woman, the women in this pilot shared their experiences of being offered and of completing HIV testing during their pregnancy.[1] The paper addresses the specific question of whether, in the context of promising new interventions to reduce perinatal transmission and rising levels of HIV infection among Canadian women of child-bearing age, the drive to screen as many pregnant women as possible has resulted in an abrogation of a woman's right to the established principles of HIV testing. Specifically, what is the evidence from the women in this pilot of adherence to the principles that testing for HIV should always be voluntary and should always be carried out only after the person has given their informed specific consent?

Introduction

Prevention of Perinatal Transmission as a Priority

Prior to 1994, in the absence of effective perinatal preventive treatment, the general consensus was that the testing of pregnant women would not significantly further any public health policy objective to prevent the spread of HIV. HIV testing in pregnancy was therefore at the request of the woman or the judgment of the physician.[2]

Since that date, the convergence of the promising results of a preventive treatment regime (PACTG 076) that achieved a near two-thirds reduction in the anticipated rate of perinatal transmission[3] and the worrisome epidemiologic data documenting a rise in HIV infection among Canadian women of child-bearing age[4] has called for a reconceptualization of the earlier public health position on HIV testing in pregnancy. The early detection of HIV in pregnancy has now become a priority and has spurred the international development of programs, policies, protocols, and guidelines aimed at increasing the number of pregnant women who are tested for HIV.

HIV Testing of Women as Mothers

While increasing the number of pregnant women who agree to test is an important objective, the process must be accomplished in a way that does not minimize or compromise pregnant women's needs or rights to best practices in HIV counseling and testing.

In the rush to respond to innovative therapy that reduces the risk of perinatal transmission, is a new risk introduced – a risk that the basic rights of the mother will be swept away, as is suggested by members of the legal community? Is there evidence from pregnant women that their needs and rights to best practices in HIV counseling and testing are being swept away in the pressure to test women as mothers? Are the established principles of HIV testing maintained in the special circumstances of a program whose primary focus is to reduce perinatal transmission and perhaps only secondarily to address the issue of HIV infection among women?

Extracts from the women's narratives relating to voluntary testing and informed consent are presented in this paper and analyzed in terms of the *Counselling Guidelines for HIV Testing* prepared by the Expert Working Group on HIV Testing: Counselling Guidelines, published by the Canadian Medical Association (Counselling Guidelines).[5]

Research Design and Methods

Semi-structured interviewing was selected as the best means to achieve the active involvement of the women in the compiling of data about their perceptions and experiences of HIV screening during pregnancy. The interview was an inductive process with few predetermined questions. It was also an iterative process, in that questions were added both within and between interviews, as unanticipated patterns emerged.

This pilot phase involved ten women recruited through strategies aimed at accessing women from a range of life situations considered likely to impact on their experience of the counseling and testing process.

The in-depth exploratory interviews were facilitated by a woman researcher, were audio-taped with the women's consent, typically lasted between one and two hours, and ended with an extensive debriefing and an opportunity to ask questions. The women were compensated $30 for their time.

Data analysis was exploratory and descriptive, in line with the objectives of the research study. The transcript of each taped interview was read three times by two researchers with experience in the analysis of qualitative research. Categories for the preliminary analysis were independently developed and collectively discussed and refined. A resultant discrete number of categories with consistent descriptors of coding choices were applied to the data.

Results

The Women in the Study

At the conclusion of the interviews, eight of the women were given the choice of responding to some basic, positioning socio-demographic questions. The average age was 32. Two had not completed high school, four had completed an undergraduate degree, and two had completed their education at the Masters' level. Two reported that they were receiving welfare, two reported household incomes between $50,000 and $60,000, two had incomes above $80,000, and two above $100,000. Two had recently given birth, one was in her first trimester, four were in their third trimester, and one was due to give birth "at any moment."

Variability in Prenatal HIV Screening Experience

The Counselling Guidelines recommend offering HIV testing and counseling to all pregnant women.[6] Were these pregnant woman all offered HIV testing and counseling?

Based on the narratives shared with us by these women, there appears to be little consistency in their individual experiences of the offer of HIV counseling and testing as a feature of prenatal care. Of the ten women, only four had been offered the option of being tested, an offer that was taken up by three of them:

> My doctor recommended it. She suggested that I have an AIDS test. That she wanted me to have the HIV test. I guess to make sure that everything's OK with me and the baby.

> I was asked by my obstetrician whether I wanted to actually have an AIDS test. And I asked whether it was mandatory, and I was told no, it wasn't. Therefore, my husband and I said, "No, there's no need." ... It was very much, "Would you like to have the AIDS test?" And, we were sort of looking at each other and saying no.

Two women understood the HIV test to be a mandatory feature of prenatal care and, as one woman explained, assumed that they did not have a choice regarding consent to testing:

> Well, I assumed that it was mandatory as I saw it on the requisition form. I was speaking to the nurse at the time and she actually provided me with a brochure that I have in my hands here – HIV testing brochure produced by [name of the hospital]. I assumed it was just for my information, and I wasn't told – I assumed it was mandatory, so I didn't question it at all. And yeah, I went for testing right away.

One woman was positive at the time of her pregnancy. Three women were very clear that they had not been informed about the possibility of HIV testing in their pregnancy or had not been offered the option of being tested:

> As far as I know, I was not tested for HIV.

> That doctor and I never discussed HIV.

One of these three women recounted explicit details of her understanding of the maternal triple-screening and hemoglobin tests she had completed during her pregnancy, and was very clear that nobody had talked to her about testing for HIV during her pregnancy:

> During my pregnancy – no. And I never thought to ask. It never even crossed my mind. But that's probably because – no, I shouldn't say probably because I'm not sure I would have thought of it anyway. It just wasn't in the forefront of my mind.... I've only seen my GP and my gynecologist and various nurses, and none of them brought it up.

Voluntary Testing

The underlying principle in testing for HIV established in the Counselling Guidelines is that "testing for HIV should always be voluntary."[7] Based on the narratives shared with us by the six women with whom testing for HIV had been raised or was something they were aware of in their pregnancy, how well do their experiences measure up to this protocol? Was HIV testing in pregnancy perceived by these women as voluntary?

A majority of the women felt that they had no choice but to undergo HIV testing:

> I don't remember there being that much explanation about the tests themselves. It's more like this is what you have to be tested for.
>
> I probably could have said "No, I don't really want to." But I kind of felt that it was just part of the whole package and I didn't think I had a choice.... I didn't feel it was an offer. Nor did my husband – he was there when my nurse spoke about it.

Interestingly, two of the women who thought that testing for HIV was not "part of the whole package" but rather was at the discretion of the pregnant woman herself, shared their perceptions of their health-care provider's influence on their decision-making. Although the first woman was able to resist the influence and assert her wish not to be tested, the second woman felt that she had little choice:

> I felt that she did definitely want me to have it done, but she obviously realized that I was adamant that we felt we didn't need that. But I did feel that she did want us to have it done.... I would think that there are other people who would find it difficult to refuse that. I'm fairly strong-minded and I'm very sure about my views, so therefore it wasn't, especially on that matter, something that I could be pushed into. But I think that there was definitely a pressure there, that they wanted to have it done.
>
> My doctor told me she wanted me to have it. She wasn't leaving me much of a choice. I could have said "no" but she strongly recommended that I have it. So I did.

The perceived pressure from a woman's physician to agree to testing may be less direct than the experiences of these two women, but is no less real in terms of acting to minimize a woman's control over her own decision-making. One woman explained how her concern for the continuation of her antenatal care featured in her decision to accept HIV testing even though she felt she had not consented to it:

> This is going to happen. That's how it [the HIV test] was presented to me.... I sort of felt like, this is a bit obnoxious. But I'm not going to make a fuss because I know it is not an issue for me.... I mean, it's a very delicate thing, your relationship with your obstetrician. Because as much as you want to stand up for yourself, the bottom line is you also want to please your obstetrician because you want him to be there for you. It's complicated. Because you know the risk is, if he doesn't like you, he won't show up for your birth.... There are a lot of things I felt about pregnancy that I felt "I just have to do them" because I have to please my doctor. Because at the end of the day I really want him to like me and I want him to come to my birth. Because these guys are pressed for time and they don't make guarantees. But they will come if they take a shine to you. And the last thing I wanted to be was a pain in the arse.

It has been suggested that including the request for testing for HIV on the same requisition form as other maternal screening tests suggests that it is a routine test that women have little option but to accept. Such appears to be this woman's experience:

> I was given a requisition form with all manner of other tests on it. I recognized my test for my thyroid, and I think maybe one or two other tests on it. And I did notice "HIV" written in, which I wasn't told about and didn't question or ask why because I was just assuming it was mandatory at that point.

Only one woman, at the time of a preconception checkup, told us that she felt she was agreeing to be tested of her own accord:

> He was filling out the requisition form, I guess, and said "we can also screen for HIV if you're interested." He said, "I recommend that for women who are considering conceiving, if you don't have any objection to it." And I said, "No, I'd like that actually." ... I was under the impression, at least from my recollection, that I could have said, "No, I don't want you to screen for that." Although that wasn't an option for me. But I don't think he was in any way saying, "I want you to do this, or you have to do this." It was just, we can do this all at once kind of thing.

Issues of Informed Consent

In addition to the requirement that HIV testing be voluntary, the Counselling Guidelines stipulate that "testing for HIV should always be carried out only after the patient has given informed consent." In addition, in the case of pregnant women, it is suggested that "if the woman has chosen to be tested, obtain and record receipt of informed consent."[8]

Did any of the five women who had been tested for HIV in their pregnancy feel they had given their informed consent to have the HIV test?

Most of the women were very clear that they had not given their consent to being tested:

> It wasn't a consent really. It was more like, this is the way it's going to be.
>
> ("Did you get a sense that your consent was asked for before you tested for HIV?") No. Not at all. I felt that it was, as I said before, part of the test and I just went along with it.
>
> ("Did you get any sense at all that your consent was asked for in having the test done?") No. But at this point it wasn't even mentioned orally that this [testing for HIV] was going to be one of the tests.
>
> ("Did you get a sense you could have agreed or not agreed to have the test?") No, I thought it was mandatory, so I didn't question it. I didn't have much of a problem with it. If I would've, I probably would have expressed some negative thoughts. But I didn't have a problem with it. It was more like, "This is what you are getting tested for today."

One woman, who felt she did not have much choice in being tested for HIV in her pregnancy, shared with us her thoughts concerning the lack of consent that was required for her HIV test. However, as she perceived herself at low risk, the test "was the least of my issues at that point."

> He may have at some point said, "And now you're also going to be tested for HIV. It's standard procedure." Something like that. He definitely minimized it and wanted me to go along with it.... I didn't get the feeling that I was going to have a choice anyway.... I believe I was tested. It wasn't such a terrible experience. It just, it was a bit odd and I found it ... bizarre. And I remember questioning whether, you know – how do, how, what are the, where are the privacy laws in all of this? Can they just do this? But then I remember thinking "well, you know, what does it matter?" You know, because I know I'll come out clean and I'm substantially certain that I'll come out clean.

Only one woman's experience could be judged to meet the standard of consent specified in the Counselling Guidelines:

> ("So, I hear you say that you felt that you were giving your consent and that the choice was left with you?") Yeah. I was in perfect control as to whether I wanted to be tested or not. That was good.

Conclusion

Recent Canadian work examining the medical and legal parameters surrounding HIV testing and pregnancy concludes that any measures such as testing without informed consent clearly involve an undue interference with the autonomy rights of pregnant women and cannot be justified as a matter of law or medical necessity.[9] Indeed, in her review of Canadian jurisprudence on the issue, Stoltz[10] suggests that a physician who tests for HIV without obtaining informed consent as detailed in the Counselling Guidelines would be vulnerable to a civil action from the person so tested and to prosecution for professional misconduct by their licensing body.

In order for pregnant women to increase control over their own health and that of their unborn children, there is clear value in all pregnant women being afforded the opportunity to know their HIV status. However, the voices of the women in this pilot study as they described their experiences of HIV counseling and testing suggest that the autonomy rights of pregnant women may well be at risk in a program in which the current emphasis is on potential HIV infection of the fetus rather than on potential or actual infection of the pregnant woman.

– Lynne Leonard & Louise Shap

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[1] L Leonard et al. Pregnant women's experiences of screening for HIV in pregnancy: What they have to say about what constitutes an appropriate policy for the HIV testing of pregnant women in Canada. A pilot study. Technical report to Health Canada. Ottawa: Health Canada, 1998.

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

[3] EM Connor et al, for the Paediatric AIDS Clinical Trials Group Protocol 076 Study Group. Reduction of maternal–infant transmission of human immunodeficiency virus type 1 with zidovudine treatment. *New England Journal of Medicine* 1994; 331: 1173-1180.

[4] The total number of reported AIDS cases among adult women (delay adjusted) has increased from an average of less than 10 cases per year in the early 1980s to an average of 143 cases per year in 1995-97. In addition, the proportion of AIDS cases among women has increased over time, particularly recently, from 6.3 percent of all AIDS cases before 1990 to 7 percent during the period 1990-95 and 13 percent in 1996-98. Of particular concern in this context is that the majority of reported AIDS cases among women are among women of child-bearing age in the 30-39 age group. HIV data also suggest increasing infection among Canadian women. Whereas before 1995 women represented 9 percent of all positive HIV test results with known gender, this proportion doubled to 19 percent during 1995.

[5] Expert Working Group on HIV Testing: Counselling Guidelines. *Counselling Guidelines for HIV Testing*. Ottawa: Canadian Medical Association, 1995.

[6] Ibid at 17.

[7] Ibid at 5.

[8] Ibid at 18.

[9] Jürgens, supra, note 2; L Stoltz, L Shap. *HIV Testing and Pregnancy. Medical and Legal Parameters of the Policy Debate*. Ottawa: Health Canada, 1999.

[10] Ibid.

DISCRIMINATION

Discrimination and Human Rights Abuse in Russia

AIDS-related discrimination and human rights violations in Russia are widespread. The problems have been documented in a report prepared by the Russian NAMES Foundation, a national non-profit organization that provides services in HIV/AIDS awareness, offers social and psychological support to people affected by the AIDS epidemic, and advocates effective and non-discriminatory AIDS policies. The report is entitled *AIDS-Related Violations of Human Rights and the Russian Legislation*. The information presented in the report is based on testimonies by people with HIV/AIDS, their friends and families, medical professionals, state officials, workers at non-governmental organizations, and other citizens. The following is an edited version of the report.

The Russian NAMES Fund has consistently observed and documented instances of discrimination and human rights violations in Russia. Many regulations and practices in Russia not only fail to facilitate effective AIDS education and prevention efforts, but in fact hinder these efforts by promoting discrimination against people with HIV/AIDS or vulnerable populations.

An important obstacle preventing people with HIV/AIDS from effectively exercising their rights is the inconsistency of Russian legislation. Russian laws and regulations often contradict each other and are frequently incompatible with the Constitution of the Russian Federation and the international human rights agreements signed by Russia.

Listed below are explanations and a few examples of the most common human rights violations in Russia in the context of HIV/AIDS. They have been grouped into eight categories of rights:

- the right to voluntary HIV testing and the right not to be subject to mandatory testing;
- the right to confidentiality of medical diagnosis;
- the right to labour and freedom of discrimination in employment;
- the right to health care and free medical assistance;
- access to information;
- freedom from torture and inhumane and degrading treatment;
- the right to respect for one's private and family life, home, and correspondence;
- the right to education and to freedom of choice in education.

Right to Voluntary HIV Testing and Right Not to Be Subject to Mandatory Testing[1]

In Russia, according to a government decree,[2] HIV testing is mandatory only for a limited number of professions, such as health-care workers who perform medical examinations, diagnosis, treatment, and care of people with HIV/AIDS.

However, in practice, many other professions are subject to mandatory HIV testing, including salespeople, staff at restaurants, cafes, and other food-catering businesses (who are required to keep sanitary booklets containing HIV test results and other health information),[3] drivers of public transportation (who must be tested every six months to keep their jobs), and police officers (who must have an HIV test before they are hired).

Furthermore, other populations are systematically tested under various circumstances that are not prescribed by law. These include:

- children and young people, who are tested as part of medical checkups required by summer camps and sanatoriums, and when enrolling in colleges and universities;
- senior citizens, who are tested when entering institutions for the elderly; and
- women who are pregnant, including women applying for an abortion.

In most cases, people do not have a choice whether or not to get tested. Often they are not aware that the requirement to take an HIV test under these circumstances is illegal; besides, they know that access to the services will be denied if they refuse to take the test.

Foreigners are required to provide a certificate showing a negative HIV test result when they apply for a Russian visa for a period longer than three months. In Russia, foreigners must get tested if they want to extend their visa, apply for a job, or obtain accommodation on a university campus, even though there is no legal basis for mandatory testing of foreigners on Russian territory.

In December 1997 the head of the Moscow Sanitary Surveillance Department issued a regulation[4] mandating HIV testing of all foreigners, including nationals of countries in the Commonwealth of Independent States (with the exception of Belarus) who come to work in Moscow.

Construction companies frequently recruit workers in Ukraine, Moldova, Belarus, Armenia, the former Yugoslavia, Turkey, and Poland. When they enter Moscow, these workers are tested en masse for HIV at the request of the employers.

With respect to the health sector, in November 1995 the Moscow Health Department and the Moscow Committee of Sanitary Surveillance jointly issued a list of clinical and epidemiological guidelines for HIV testing. These guidelines, which must be observed by all public health-care institutions in Moscow,[5] do not state clearly whether such testing should be voluntary or mandatory. The Federal AIDS Law requires that HIV testing be voluntary and accompanied by pre- and post-test counseling.[6] In practice, however, patients are seldom given the right to make an informed choice based on knowledge of the purpose, procedure, and possible consequences of the test, and none of the 10 state-run anonymous testing sites in Moscow provide adequate pre- and post-test counseling. If the screening test result is positive, the patient is simply told that the test is unclear, and is referred to the Moscow AIDS Centre (which treats all people with HIV/AIDS in Moscow) to confirm the result. Experience has shown that people with positive screening test results who do not receive counseling about the meaning of the test, the importance of seeing a qualified HIV/AIDS specialist for maintaining their health, and their right to keep their HIV status confidential, usually choose not to go to the AIDS Centre and thus deprive themselves of the medical care to which they are entitled.

Virtually all patients are tested for HIV infection before being hospitalized in any public health-care institution in Moscow. Pregnant women are tested before delivery or before an abortion is performed. In theory, a patient has the right to refuse to be tested, but risks being denied access to treatment and care by the institution. It should be noted that patients have a very limited choice (and sometimes no choice at all) of health-care institutions because most medical services in Russia are based on a territorial principle – they are accessible only to residents of a particular area. There is hardly any medical institution in Moscow that would hospitalize a patient with an unknown HIV status, or a patient with HIV.[7] If a pregnant woman refuses to take the test, she will be automatically referred to a specialized infectious diseases clinic for delivery, without being given any other choice.

Right to Confidentiality of Medical Diagnosis[8]

Often a patient's right to confidentiality of their HIV diagnosis is not observed. This leads to serious negative consequences for a person's private and professional life. For example:

- In March 1998, Andrei M was tested for HIV while he was hospitalized, without his knowledge or consent. The test was positive. By the time the test results came back, Andrei had already left the hospital. The hospital informed the Moscow AIDS Centre that Andrei was HIV-positive. To get Andrei to come and register at the Centre, a request was sent to his local health-care clinic mentioning his HIV diagnosis and his home address. Now Andrei's diagnosis is known to all staff at the local clinic.
- In December 1997, a patient diagnosed with pneumonia was admitted to hospital. He was tested for HIV but died before the test result came back. The test result was positive. The patient's physician, who was head of the department, disclosed the deceased man's HIV diagnosis to many people at the hospital. When the man's friends came to the hospital to pick up his possessions, a cleaning woman said to them, "You came about that guy with HIV." Later, in the hospital lobby, with many people present, the physician rudely chastised the deceased patient's friends for not having warned the

hospital of his HIV diagnosis. The physician said that he would have to discard all medical equipment used to treat the patient. These statements by a senior hospital official reveal a lack of basic knowledge about HIV transmission and about universal precautions to prevent the transmission of HIV and other bloodborne infections in a health-care environment. Subsequently, the physician who performed the autopsy told the deceased man's mother that her son died because he was homosexual. The relatives were told that the official death certificate would carry the HIV diagnosis. However, the relatives paid a bribe and the diagnosis on the death certificate was changed.
- When migrant workers from neighbouring countries get tested, their test results are given to the company director or to a representative of the workers, which results in disclosure of HIV status.

Right to Labour and Freedom of Discrimination in Employment[9]

The fact that various professions require HIV testing limits employment opportunities for people with HIV/AIDS.

Although no cases of outright refusal to hire a person based on their HIV status have been documented, for reasons that are obvious, people with a positive HIV diagnosis will not come back to an employer that requires an HIV certificate. Furthermore, an experiment staged by a journalist at a major Moscow-based newspaper demonstrated that a person with HIV/AIDS will be rejected by most Russian and foreign employers in Moscow. The reporter called a number of companies, including McDonald's, asking for a job interview. At first, prospective employers sounded interested, but when the reporter said he was HIV-positive he was immediately advised to apply to some other company.[10]

Many regulations and practices in Russia not only fail to facilitate effective AIDS education and prevention efforts, but in fact hinder these efforts.

If the HIV status of employees with HIV/AIDS becomes known to their colleagues or employers, they will be forced to leave their jobs. Although HIV is never mentioned as an official reason for dismissal, employers find various pretexts to get rid of an HIV-positive employee.

The same thing happens when the employer simply suspects that an employee may have HIV. In late 1997, Pavel K, a person with HIV/AIDS whose HIV status was not known at work, worked as a restaurant chef. Pavel lived with a roommate who was also HIV-positive. Pavel's roommate died of AIDS. The restaurant manager, who knew that the two men shared an apartment, harassed Pavel with insensitive questions and innuendoes, and finally demanded that he produce an HIV certificate. Aware that his HIV status would be disclosed and used as a reason for dismissal, Pavel chose to leave the job.

The Right to Health Care and Free Medical Assistance[11]

The Federal AIDS Law states that every person with HIV/AIDS has the right to receive free and adequate medical care. This right assumes that federal funding of HIV-related health care will be available to cover medications, treatment facilities, and training for medical staff. However, in practice, most medical institutions are funded by insurance companies from local budgets. Most local budgets, with the exception of those of Moscow and St Petersburg, do not have the capacity to provide residents with HIV/AIDS with the necessary diagnostic services, medications, and treatment. Consequently, adequate medical care is not guaranteed to all Russians with HIV/AIDS. Access to adequate care depends to a very large extent on where one lives and where one is registered.

To obtain decent care, people with HIV/AIDS are usually forced to move to Moscow and St Petersburg. However, a strict system of residence registration exists in Moscow, a system that is incompatible with Russia's own legislation, as well as the internationally recognized human right to freedom of movement and choice of residence.[12] As a result, people with HIV/AIDS who come to Moscow in pursuit of their legal right to adequate medical care have to stay there illegally, without registration. Once there, they run the risk of being harassed by the police and of being charged high rents for accommodation.

In addition, non-residents receiving treatment in Moscow are deprived of their right to free medical care if they do not possess a Moscow health insurance policy. In Moscow, free health care is available only to residents who are permanently or temporarily registered with the police, and who possess a Moscow health insurance policy.

Although residents of Moscow Region (the area outside the city of

Moscow) and some patients from other regions of Russia are "assigned" to the Moscow AIDS Centre and are entitled to its services, they have locally issued health-care policies and thus are expected to obtain medications (which are theoretically free for people with HIV/AIDS) in their home localities. In many cases the expensive medications used in HIV treatment protocols are not available locally due to limited local funding. As a result, patients end up having to pay for the medications in Moscow.

For example, Vladimir, a person with HIV/AIDS, left his small provincial home town and moved to Moscow to receive adequate medical care. He is currently being treated by physicians at the Moscow AIDS Centre. Because Vladimir does not have a Moscow health insurance policy, he has to spend over US$400 every month to obtain antiretroviral medications.

Some patients need specialized medical services that the Moscow AIDS Centre cannot provide because it does not have specialists such as ophthalmologists and neurologists on staff. Very often it is impossible for patients to obtain such services in public health-care clinics outside the AIDS Centre because the medical staff of these clinics refuse to treat HIV patients. It is not always clear whether they do so in compliance with their clinic's unwritten policy, or at their own discretion (which would constitute a breach of medical ethics). In any event, even though failure to provide treatment in these situations is a criminal offence in Russia, there are no known cases of a health-care worker being prosecuted for refusing to treat a person with HIV/AIDS.[13]

Access to Information[14]

The absence of consistent and targeted education on HIV/AIDS contributes to AIDSphobia, discrimination, and ignorance among the Russian people. Ignorance is prevalent not only among the general population, but also in the medical community.

An important (though rarely cited) factor contributing to the lack of AIDS-related information is the secrecy that surrounds information that should be freely available. National, departmental, and local AIDS policies should be transparent and available to the public. Specifically, Russian citizens and visitors must have the right to know exactly under what circumstances and by what procedures they can be tested; what the consequences of a positive HIV test are; and what their options are if they are tested for HIV illegally, or if they are denied access to medical assistance, employment, education or child care on the grounds of a positive or unknown HIV status. This information must not only be open and easily accessible, it should also be proactively and consistently communicated to the public.

The Federal AIDS Law defines the rights and responsibilities of citizens and organizations in the context of the AIDS epidemic. The law contains a number of general provisions that require further clarification in terms of their application and enforcement. The law leaves many questions unanswered. For example: What is the procedure for testing foreign nationals on Russian territory? What measures can be taken against officials, organizations, and individuals who discriminate against people with HIV/AIDS?

The vagueness of the Federal AIDS Law gives officials at various levels the freedom to interpret the law as they wish. For example, the Moscow City Health Department and the Sanitary Surveillance Committee have issued a large number of regulations that constitute the city's AIDS policy. Frequently, these regulations are intended for internal use and are never officially publicized, as opposed to federal laws and government decrees, which are published in major newspapers. Furthermore, these regulations violate Russian legislation and basic human rights and freedoms. These departmental and local regulations are particularly dangerous because the people affected by them do not even know what the regulations say.

The secrecy of Moscow's AIDS policy makes residents and visitors vulnerable to discrimination and abuse regardless of their HIV status. The following story illustrates this vulnerability.

In March 1998, Victor, a salesman in a store, was supposed to be issued a sanitary booklet containing his health information, including his HIV status. Sanitary booklets are attached to employees' records and are accessible to a broad range of people, including employers and outside inspectors. Victor, who is HIV-positive, was afraid of losing his job and having his HIV status disclosed. Victor was never informed that he has the right not to have his HIV status included in the booklet because salespeople are not on the list of professions legally subject to HIV testing. Nor was Victor aware that his HIV-positive status does not give his employers the right to fire him.

Medical information is of vital importance to people with

HIV/AIDS. The effectiveness of antiretroviral medications depends greatly on the patient's compliance with the treatment regimen and on good communication with the doctor. If patients do not comply, they may be denied further antiretroviral treatment. However, health-care workers sometimes fail to communicate this important requirement to patients and to ensure that the patients fully understand the requirement.

In September 1997, Artyom was started on therapy with AZT and Crixivan. During the three months that he was taking the medications, he often missed doses and drank alcohol, both of which are violations of the treatment protocol. Victor says that his physician did not explain that doses should never be missed and that alcohol is not allowed. When the physician discovered that the patient was not complying, the treatment was stopped.

Finally, people with HIV/AIDS who are in detention or in correctional institutions do not have access to any HIV/AIDS-related information.

Freedom from Torture and Inhumane and Degrading Treatment[15]

In the context of HIV testing, people are sometimes subjected to humiliating and abusive treatment, as the following story reveals.

Andrei Petrovich donated blood for several years at various donor sites. In late 1996, the blood he donated was tested for HIV and found to be positive. This information was sent to the local clinic in Andrei's home town, a small place near Moscow. He was forcibly taken from his home and placed in an isolated ward at the local hospital. He was denied contact with anybody. His food was given to him through an opening in the door. After what was termed an "epidemiological investigation," the medical staff determined that he was "just a homosexual" and not a drug addict, as they originally suspected. Subsequently, he was released.

> The absence of consistent and targeted education on HIV/AIDS contributes to AIDSphobia, discrimination, and ignorance among the Russian people.

The Right to Respect for One's Private and Family Life, Home, and Correspondence[16]

The Russian Criminal Code contains a provision that makes people with HIV/AIDS liable for knowingly "putting another person at risk of infection."[17] However, the law does not say what actions would constitute "knowingly putting another at risk of infection." Does it include sex with a condom? Does it include seeking medical assistance outside the AIDS Centre without disclosing one's HIV status to the health-care worker, although all health-care workers are supposed to use universal precautions against the transmission of HIV and other bloodborne infections with all their patients? Is a person with HIV/AIDS who was sexually assaulted, and who infected the perpetrator as a result of forced sexual intercourse, still criminally liable? The answers are not obvious.

In 1996, Inna, an HIV-positive woman, lived in a small town near Moscow with a violent and abusive man whose HIV status was unknown. Inna reported the abuse to the police, and her partner was convicted and put on probation. The man found out he was HIV-positive and, wishing to punish Inna, charged her with infecting him. She was prosecuted under the Criminal Code. Inna argued that her partner had known that she had HIV and that they always used condoms, with the exception of one incident when her partner beat her unconscious and raped her. The criminal case was launched two years ago and is ongoing. Meanwhile, Inna's health has severely deteriorated.

The Right to Education and to Freedom of Choice in Education[18]

Under the Federal AIDS Law, it is illegal to deny people access to educational institutions on the basis of HIV status. However, there have been many cases where children living with HIV were refused admittance to a kindergarten or school.

Here is one example. Lena was infected with HIV in a hospital when she was undergoing surgery. Her parents abandoned her. Lena lived in the children's ward of the Moscow AIDS Centre for five years. She was denied admittance to the kindergarten and, later, to school because of her HIV infection. Lena was taught to read and write by a private tutor who subsequently refused to teach her.

Recommendations

To address the current problems, and to prevent future human rights violations, the following minimum measures are recommended:

- That AIDS legislation (at all levels) be amended, bringing it in line with the Constitution of the Russian Federation and international human rights agreements.

- That appropriate measures be taken to ensure transparency of federal, departmental, and local AIDS policies, and that the main provisions of these policies be communicated to the public on a regular basis, with necessary interpretations and clarifications.
- That the enforcement of the Federal AIDS Law and other relevant legislation be improved, specifically the provisions on obligatory pre- and post-test counseling, on the limited list of professions that can be subjected to mandatory testing, and on the consequences of the violation of these provisions.
- That all Russian citizens with HIV/AIDS have equal access to adequate HIV/AIDS-related medical care.
- That mechanisms be developed to ensure accountability of government officials and private citizens for violations of the Federal AIDS Law.

– prepared by The Russian NAMES Fund

For more information about the material in this article, the Russian NAMES Fund can be reached at PO Box 130, Moscow 113303, Russia. Email: <names@glasnet.ru>. More information about HIV/AIDS in Russia can also be provided by AIDS infoshare, PO Box 51, Moscow 105037, Russia. Email: <infoshare@glas.apc.org>; website: <www.openweb.ru/infoshare/eng/index.htm>.

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[1] Articles 7 and 8 of the Law on the Prevention of the Spread of the Disease Caused by the Human Immune Deficiency Virus on the Territory of the Russian Federation (Federal AIDS Law).

[2] Government of the Russian Federation. Decree No 877 of 4 September 1995.

[3] Regulation No 6 of 31 March 1997, on the Extraordinary Hygienic Certification of the Decreed Contingent and on the Introduction of Standard Individual Medical Booklets in Moscow.

[4] Regulation No 25 of 11 December 1997, on the Order of Hygienic Certification and Medical Testing of Foreign Citizens Working in Moscow.

[5] Appendix 2 to Regulation No 676/144 of 27 November 1995, by the Moscow Health Department and the Moscow Committee of Sanitary Surveillance.

[6] Article 7, p 6 of the Federal AIDS Law.

[7] All patients with HIV are expected to receive treatment in AIDS Centres. This applies to any medical condition they may have, whether HIV-related or not.

[8] Article 61 of the Russian Federation Law on the Protection of Citizens' Health.

[9] Article 37 of the Russian Constitution.

[10] *Na Rabotu so SPIDom* (*Getting a Job If You Have AIDS*), *Obshchaya Gazeta* 18-24 December 1997.

[11] Article 43 of the Russian Constitution; Article 4 of the Federal AIDS Law.

[12] Article 13 of the Universal Declaration of Human Rights; Article 2 (Protocol 4) of Article 8 of the European Convention for Protection of Human Rights and Fundamental Freedoms; Article 27 of the Russian Constitution.

[13] Article 24 of the Russian Criminal Code: "1. Failure to offer medical assistance to a patient by an individual who is obliged to offer such assistance in accordance with a law or a special regulation, if such negligence caused medium harm to the patient's health...".

[14] Article 8 of the European Convention for the Protection of Human Rights and Fundamental Freedoms; Articles 6 and 49 of the Russian Constitution.

[15] Article 2 of the European Convention for the Protection of Human Rights and Fundamental Freedoms; Article 20 of the Russian Constitution.

[16] Article 8 of the European Convention for the Protection of Human Rights and Fundamental Freedoms; Articles 23 and 24 of the Russian Constitution.

[17] Article 122 of the Russian Criminal Code, 1 January 1997.

[18] Article 26 of the Universal Declaration of Human Rights; Article 2 (Protocol 1) of the European Convention for the Protection of Human Rights and Fundamental Freedoms; Article 43 of the Russian Constitution; Article 17 of the Federal AIDS Law.

Legal, Ethical, and Human Rights Issues Facing East and Southeast Asian-Canadians

In the last issue of the *Newsletter*, we reported about a project on HIV/AIDS and discrimination in *South Asian* communities in Canada,[1] undertaken by the Toronto-based Alliance for South Asian AIDS Prevention (ASAP). In this issue, we report about another project focusing on issues of discrimination in ethnocultural communities in Canada: a project on legal, ethical, and human rights issues facing *East and Southeast Asian*-Canadians, undertaken by a Toronto-based AIDS-service organization, the Asian Community AIDS Services (ACAS). The project concluded that "societal discrimination, systemic service deficiency and resource allocation barriers contribute to a hostile environment that challenges the self esteem, sense of efficacy, health and well being of Asians infected and affected by HIV/AIDS."[2]

The Project

The goal of the project was to explore the many challenges faced by Asian people with HIV/AIDS in Canada, and to make recommendations that address the gaps and barriers in services for them.

The majority of participants came from Toronto and Vancouver – the only Canadian cities with AIDS service organizations targeting the Asian community (ACAS in Toronto and ASIA in Vancouver). In total, 38 individuals participated in the study:

- 16 Asian people with HIV/AIDS were interviewed in Toronto and Vancouver;

- 19 service providers participated in focus groups held in Toronto, Calgary, and Vancouver; and
- three key informants were interviewed in Toronto and Vancouver.

Results

The various chapters of the project report highlight "complex and unique barriers faced by Asian persons with HIV/AIDS in their daily struggles with HIV/AIDS."

The section called "Living with HIV/AIDS: The Individual" discusses how, for Asian people with HIV/AIDS, their sense of identity is closely related to their health status, sexual orientation, ethnocultural background, and religious affiliation. Due to conflicting values, they often "find themselves caught between the Asian community and the gay community." Becoming HIV-positive redefines how Asian people with HIV/AIDS live, their relationship with family, friends, and partners, and generally, their social life.

The section on "Community Living: The Social Context" emphasizes that there is a high level of diversity within ethnocultural communities. However, it also points out that these communities

> share some deeply-rooted social conventions which place heavy emphasis on family and community and which are framed within a patriarchal, heterosexist model. In this context, there is little tolerance for alternative lifestyles.

Almost all the study participants came from marginalized sectors of the Asian communities. They included gay Asians, intravenous drug users, and women. As the report says,

> [t]heir alternative lifestyles and subordinate social positions are highly stigmatized. Homophobic, racist and sexist stigma, in turn, prevent PHAs [people with HIV/AIDS] from receiving the necessary support from both their ethnocultural community and mainstream society.

Contrary to the misconception that PHAs are only users of service, many do volunteer their time and energy towards helping others. They contribute to their communities by sharing their experiential knowledge as an Asian living with HIV/AIDS. As role models, they raise the awareness level and the profile of HIV/AIDS by breaking the silence in our communities.

The report shows how the lack of basic information on HIV/AIDS in the Asian communities seriously hinders the effectiveness of HIV/AIDS prevention, education, and support; and how it affects access to medical treatment, testing, and diagnosis for many Asian Canadians, often leading to poorer health outcomes.

The section on services for Asian people with HIV/AIDS concludes that many have trouble accessing appropriate services, and that service providers have limited resources to address the multiple needs of Asian people with HIV/AIDS. On the one side, many social service agencies with a mandate to serve Asians are often homophobic and AIDSphobic. On the other, mainstream AIDS service organizations are not always equipped to serve the needs of Asian people with HIV/AIDS. And those few organizations whose specific mandate it is to serve the needs of Asian people with HIV/AIDS are often underfunded. Many worry that the lack of services and of culturally and linguistically appropriate HIV/AIDS education materials and treatment information seriously limits the communities' ability to adequately address the needs of Asian people with HIV/AIDS in Canada. Also of concern is that, within the Asian communities, there is a serious lack of dialogue and communication to address the impact of HIV/AIDS in Asian communities.

The section on "Women and HIV/AIDS" shows how the traditional patriarchal system perpetuates sexism and power imbalances for Asian women. The subordinate role within the family structure further places women in a position of lower priority compared with men. The report states:

> Women in our community often sacrifice their own needs before other members of the family. As a result, there is little opportunity for them to up-grade language skills and seek career development and empower themselves with the skills and knowledge that would protect them.

It concludes that women need better access to available services and specific programs that target their needs; and that Asian communities must recognize how gender and family play a central role in the power imbalances between the sexes and how this impacts on the lives of Asian women with HIV/AIDS.

Generally, the report concludes that Asian people with HIV/AIDS

> have more difficulty in dealing with their psychosocial issues compared to their mainstream counterparts. Although there has been improvement over the years, support for Asian PHAs still lags behind that of the mainstream PHA community due to the lack of infra-structure and resources in addressing the specific needs of Asian PHAs. Their psychological barriers to accessing services are compounded with cultural taboos and societal stigmas. Low self-esteem and inadequate supports limit Asian PHAs' capacity for self-advocacy.

It further concludes that homophobia is a major concern within the various Asian communities, and that it has major implications for efforts to address HIV/AIDS: "The often negative images of gay, lesbian and bisexual people portrayed by Asian media, together with the misconception that HIV/AIDS is a Caucasian gay man's disease continues to work against the prevention and education of HIV/AIDS in our community." It continues by saying that

> preventing HIV transmission in the East and Southeast Asian communities requires eliminating racism, homophobia, sexism, and classism. In addition, we must recognize, validate and respect diversity within Asian communities. We also need to create a safe environment for Asian PHAs to receive information and appropriate services.

The last section of the report contains 22 recommendations. Among the most important are:

- Put in place mandatory diversity training for all staff, volunteers, and board members of all AIDS service organizations to raise awareness on racial, cultural, sexual, and gender differences that create power imbalances and to ensure culturally appropriate service delivery.
- Ensure that an anti-racist and anti-oppressive framework exists in the policies and mission statements of all relevant service organizations.
- Develop mechanisms within government and non-government funding bodies that allocate resources to increasing accessibility of health, social, and legal services for people with HIV/AIDS who belong to marginalized communities.
- Ensure that government funding guidelines require any research or planning initiatives conducted on legal, ethical, and human rights issues with respect to HIV/AIDS include the participation of ethnocultural communities at all levels.

– submitted by ACAS

Copies of the full Report are available through ACAS, 33 Isabella Street, Suite 107, Toronto ON M4Y 2P7. Tel: 416 963-4300; fax: 416 963-4371; email: <info@acas.org>; website: <www.acas.org>. The executive summary and recommendations are also available in French, Chinese, Tagalog, and Vietnamese.

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[1] M Radhakrishnan. HIV/AIDS and discrimination in South Asian communities: an ethnocultural perspective. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(4): 54-55.

[2] Asian Community AIDS Services. *Legal, Ethical and Human Rights Issues Facing East and Southeast Asian-Canadians in Accessing HIV/AIDS Services in Canada*. Toronto: ACAS, June 1999. The following text is a shorter, edited version of the executive summary of the project report. All quotes are from the report.

The International Guidelines on HIV/AIDS and Human Rights – Three Years On

1999 was the third anniversary of the drafting of the International Guidelines on HIV/AIDS and Human Rights.[1] This article reviews the history of the Guidelines, notes some obstacles to their implementation, and concludes with suggestions for governments and development agencies.

In September 1996, the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the (then) United Nations Centre for Human Rights convened an international consultation of experts to draft guidelines for states on HIV/AIDS and human rights.[2] The meeting aimed to translate international human rights norms into practical observance by states in the context of HIV/AIDS. The 12 principles contained in the comprehensive report of the meeting have since become known as the International Guidelines on HIV/AIDS and Human Rights. They deal with almost all legal and policy aspects of the epidemic, including civil and political rights, prevention, and care and treatment for people with HIV/AIDS.

In April 1997, the Guidelines were tabled at the United Nations' chief human rights forum, the Commission on Human Rights. Because the principles contained were still controversial, the Commission was not asked to endorse them (an unlikely outcome). Instead, the Commission requested the Secretary-General, in a vaguely worded resolution, to solicit the opinions of member governments and to provide a progress report in two years' time. It may be significant that when contacted by the Office of the High Commissioner for Human Rights (the office preparing the report) in late 1998, only 13 governments (seven percent of UN member states) responded. Even Canada, usually a strong supporter of human rights and international efforts to combat HIV/AIDS, was among those governments that did not respond.

In April 1999, in a carefully worded resolution, the Commission requested a further report on the steps taken by governments and others to promote and implement the Guidelines. (The US government representative had earlier objected that the Commission could not request a report on the implementation of a policy that it had never endorsed.) The report will be presented to the Commission in April 2001, when the issue of HIV/AIDS and human rights will again be debated.

In August 1999, the Sub-Commission on the Promotion and Protection of Human Rights also commissioned a working paper on the implementation of the Guidelines. The working paper will be prepared by an expert member of the Sub-Commission, Mr Alberto Diaz Uribe, who will report to the next session of the Sub-Commission in August 2000. He has been instructed to consult with interested parties, including NGOs, in the preparation of the paper. His report, although an independent document, will also provide a solid background for the report to the Commission in early 2001.

Even Canada, usually a strong supporter of human rights and international efforts to combat HIV/AIDS, was among those governments that did not respond.

It appears that in spite of early hopes that the Guidelines would provide a powerful policy tool for governments, policymakers, and advocates, they have generally received limited support from governments, including those in developing countries, where more than 95 percent of all people with HIV/AIDS live. Reasons may include ignorance of the Guidelines, ignorance of international human rights law, and hostility to international human rights law and its implications for national sovereignty.

First, the Guidelines have not yet been disseminated adequately or appropriately. When the Office of the High Commissioner for Human Rights and UNAIDS released a revised version in January 1998, the slim volume was designated a for-sale publication (priced at US$8 at UN bookstores). Although UNAIDS distributes a limited number of copies free of charge and has placed the full text in English, French, and Spanish on its website,[3] the document is clearly not yet in the hands of the hundreds of thousands of people in government and civil society involved in HIV/AIDS-related legal and policy issues worldwide. Nonetheless, dissemination is continuing. UNAIDS continues to work with different sectors to promote the Guidelines. A handbook for parliamentarians, based on the Guidelines and published in conjunction with the Inter Parliamentary Union, is nearing completion.

Considerable effort was put into disseminating the Guidelines to the AIDS NGO community. The International Council of AIDS Service Organizations (ICASO) was commissioned to prepare an NGO summary and advocate's guide to the Guidelines, which was then disseminated in English, French, and Spanish.[4] However, with some encouraging exceptions, the Guidelines have not yet proved to be a ready advocacy tool for AIDS activists and the community sector in the developing world.

The second reason for limited support is that the vast majority of persons involved in HIV/AIDS-related law and policy reform are largely ignorant of the international human rights law on which the Guidelines are based. It appears that many government legal and policy advisers, as well as international experts in the field, are unaware of the human rights treaty system, much less which treaty obligations apply to law and policy reform in a particular country or context. Grassroots activists find it difficult to relate the Guidelines to their everyday struggles unless they already have strong links with human rights organizations that can put the Guidelines in context. The widespread ignorance of international human rights law is clearly not limited to HIV/AIDS-related human rights, but it does have implications for the way in which the Guidelines are received in different countries. Without the backing of international law, the Guidelines may appear simply as a list of empty exhortations.

Many of the governments whose inaction has led to national HIV infection rates of over 10 percent or 20 percent are partial democracies at best.

Finally, the Guidelines may have received limited government support because many governments are still distinctly uncomfortable about the scope and implications of international human rights law itself. Rights imply obligations. Many of the governments whose inaction has led to national HIV infection rates of over 10 percent or 20 percent are partial democracies at best. Although the linkages have yet to be proven, there is an emerging pattern of underdevelopment, authoritarianism, and HIV/AIDS. Certainly the kind of community consultation and consensus that has been seen around HIV/AIDS policy development in many liberal democracies is not possible in states where civil and political rights are curtailed. International development agencies should take note.

The following steps are proposed to begin to address this situation:

First, developed countries should move to promote, adopt, and implement the Guidelines themselves, and to encourage others to do so. At its annual general meeting in June 1999, ICASO issued a statement calling on the Canadian government to take a leadership role in a campaign to encourage countries to promote and implement the Guidelines.

Second, we must work to bring the Guidelines to the desks of everyone working on HIV/AIDS-related law and policy reform in every country. This could be in the context of broader human rights education if necessary. The Guidelines, and international human rights obligations, should be an intrinsic part of the strategic planning process undertaken by national AIDS programs and other sectors. They should be as ubiquitous as the Universal Declaration of Human Rights.

Finally, international development assistance should also be directed toward strengthening government consultation mechanisms and supporting civil society in the context of HIV/AIDS. Some measure of financial aid may be contingent on progress in promoting and implementing human rights at the national level. This is controversial, but UNAIDS itself has identified political commitment at the national level as a factor to be considered when allocating limited development assistance.

Mr Uribe will no doubt be considering the above matters, and much more, when he prepares his report in the coming months.

– David Patterson

David Patterson is a human rights consultant based in Geneva. The views expressed in this article are his own and do not necessarily reflect the views of any other organization.

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[1] Office of the United Nations High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS. *HIV/AIDS and Human Rights: International Guidelines*. United Nations, New York and Geneva, 1998 (HR/PUB/98/1). Also available on the UNAIDS website at <www.unaids.org>.

[2] See *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3(2/3): 1, 45-49.

[3] See supra, note 1.

[4] For more details see: ICASO publications in the area of HIV/AIDS and Human Rights. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(2/3): 75-76 at 76. The ICASO documents are available in English, French, and Spanish; contact <info@icaso.org>.

HIV/AIDS IN PRISONS

Developing Effective HIV Prevention Programs for Inmates: Results from an Ontario-wide Survey

Many studies of the characteristics, behaviours, and prevalence of HIV among those admitted to Canadian correctional facilities indicate that inmates are at increased risk for HIV infection and that they be targeted for HIV interventions.[1] Yet the development and implementation of these programs has been much too slow and, at times, inappropriate to the prison environment. Further, the effectiveness of current and proposed policies and programs must be evaluated to ensure that the goal of reducing HIV transmission is achieved.

To address these issues, a team of University of Toronto researchers undertook a study entitled "The Social and Structural Determinants of HIV-Related Risk Behaviours among Prisoners: Implications for Prevention." This study surveyed adult males and females incarcerated in six provincial correctional centres in Ontario. The following provides a brief overview of the study and its results.

Objectives

The overall objectives of the study were to understand the prevalence and determinants of specific HIV-related risk behaviours in prison and to identify some of the barriers to the effectiveness of current and proposed HIV interventions for correctional institutions.

Methods

In 1996 and 1997, private face-to-face interviews were conducted with 439 men and 158 women incarcerated in selected minimum-, medium-, and maximum-security correctional centres in Ontario. Participants were randomly selected using the institution's nominal roll. This method of recruitment is scientifically sound and eliminates the possible stigmatization of self-selection. Participation was voluntary and confidential. All interviewers had experience with inmates, were acquainted with the prison environment, and received extensive training. Eighty-nine percent of inmates asked to take part in the study participated.

The questionnaire collected information on: socio-demographic characteristics; HIV transmission knowledge and attitudes; family and abuse history; opinions on harm-reduction techniques; incarceration history; HIV-related behaviours (sex, drugs, piercing, tattooing) prior to and during incarceration; the meaning of behaviour inside prison and outside; medical history and HIV testing; involvement in prison activities; and social support during incarceration.

Participant Characteristics

Participants ranged in age from 18 to 73 years. The majority of inmates were white (71 percent) although a sizeable proportion were Aboriginal (13 percent) or black (12 percent). A minority of inmates were married or living in a common-law relationship (30 percent). The majority of inmates (74 percent) had previously been incarcerated. Ten percent had served time in a federal prison for more serious crimes. Including time in remand facilities, participants had been incarcerated for an average of six months for their current offence.

Risk Behaviours

Many inmates were at risk for HIV through sexual and injection drug use (IDU) behaviour outside prison. Nearly one-third (32 percent) had ever injected drugs, and 17 percent had injected drugs in the year preceding their current sentence. Among the sexually active, 56 percent had two or more sex partners outside prison in the year preceding their current sentence, but only 14 percent always used condoms. Six percent were paid to have sex in this period. Efforts to provide education and counseling to reduce risk upon release should be increased.

Sexual Activity

Sexual activity occurred in provincial correctional centres, but risk-related sexual activity was low. One percent of males and females had had sexual intercourse in the past year. Non-consensual sex was rare. Condoms and dental dams were available by request from health-care personnel, yet they were not used by inmates who had sex. Reasons provided by inmates included the perception that protection was not necessary, not liking barrier methods, problems with the request-based distribution policy, and the institutional policy forbidding sexual activity. Alternative methods of condom and dental dam distribution need to be explored. Issues to be addressed include the modification of distribution practices from a request basis to free availability; encouraging positive attitudes toward condoms and dental dams; the provision of information regarding availability, distribution method, and use (particularly dental dam use); and addressing inmates' and staff's attitudes to same-sex relations.

Drug Use

Although illegal drug use inside provincial correctional centres was common practice (48 percent used illegal drugs), drug injection was rare (three percent injected). Eleven percent used injectable drugs such as heroin, cocaine, and/or amphetamines. We do not know if these drugs were not injected due to preference for a non-injection method of administration, or to lack of access to injection equipment. The strongest predictors of IDU inside prison were IDU outside prior to incarceration and extensive criminal history, including previous incarceration in a federal prison. Future studies of risk behaviour should focus on inmates with longer criminal records and those in federal prisons.

Inmates who did inject made efforts to reduce their risk. Over two-thirds did not share needles, and half of those who did share needles always cleaned them with bleach. Contrary to expectation, the prevalence of risky needle practices was the same inside as outside – inmates who injected were not more likely to share needles or less likely to clean needles. Possible explanations for this include the positive impact of HIV prevention programs outside prison and/or a reluctance to admit to unsafe injecting in the prison environment.

Inmates expressed both positive and negative attitudes toward potential bleach and needle distribution in provincial correctional centres. Advantages commonly mentioned included disease prevention and the need for bleach and needles since IDU does occur. Disadvantages commonly mentioned included negative attitudes toward drug use, the acknowledgment of correctional policy that drug use is forbidden, and possible harms related to the individual, the drug subculture, and the prison environment (eg, use as a weapon, fights).

In general, inmates were more supportive of bleach than of needle distribution. Given the number of inmates who used injectable drugs, access to injection equipment might potentially increase rates of IDU. However, access to clean equipment could reduce the risk of HIV transmission among those who inject. Programs to implement bleach kit or needle distribution should address inmates' willingness to access bleach or needles, confidentiality, anonymity, problems associated with request-based methods of distribution, staff attitudes, and impact on the prison environment.

Tattooing and Piercing

Tattooing and piercing were uncommon in Ontario's provincial correctional centres. Two percent tattooed inside in the past year, and less than one percent tattooed with points that were used. Three percent of inmates pierced inside in the past year.

Attitudes to Methadone Treatment

There was strong support for methadone in Ontario's correctional centres. Among those with a clear opinion, 77 percent expressed positive attitudes and 23 percent expressed negative attitudes about methadone availability. Lack of support was often a result of misconceptions about methadone. Sixty percent of inmates with a history of IDU believed that methadone would reduce IDU in prison. Moreover, 74 percent of inmates who had ever injected opiates in prison said they would use methadone instead of injecting. These findings indicate that carefully designed methadone programs, including education about the benefits of methadone maintenance, would reduce IDU in provincial correctional centres.

The Value of Providing Education

The study found that risk behaviour outside was predictive of risk behaviour inside. Few inmates injected in prison for the first time. The provincial correctional environment does not appear to influence inmates to try

IDU; rather, some inmates who inject on the outside continue to inject inside. Among inmates who ever injected drugs, 25 percent ever injected inside. Similarly, same-sex activity was most common among inmates who defined themselves as homosexual or bisexual, or who had engaged in same-sex activity outside prison. Since behaviour was "imported" from outside, education and behaviours learned inside may be "exported" to the outside if inmates are given the opportunity to participate in well-designed programs. Presentations of the results to correctional staff at the participating facilities indicated interest in seeing such programs developed. Programs developed by community-based service organizations should be provided while inmates are in prison, upon release, and continued outside prison.

HIV Testing

HIV testing was widely used by inmates, particularly by those at greater risk. Among all inmates, 58 percent ever tested. Twenty-one percent tested for HIV inside in the past year. This percentage was higher among people who had sex (37 percent), injected drugs (58 percent), tattooed (45 percent), or pierced (37 percent) inside prison in this period. HIV testing appears to fulfill an important role, and its provision in provincial correctional centres should be continued. Although HIV testing is not in and of itself a preventive measure, identifying new infections can improve the health of HIV-positive inmates, given current antiretroviral therapies, and prevent spread to others if HIV-positive individuals modify their risk behaviour.

Summary

This study is one of the few in Canada to examine HIV prevention programs and a broad spectrum of determinants of HIV-related risk behaviours within a prison population. It produced new information on the importance of pre-incarceration history in predicting high-risk behaviours and the use of interventions. In comparison with the federal system,[2] the prevalence of risky behaviour was lower yet the determinants of behaviour appeared similar. The study also identified ways to improve existing interventions and implications for new strategies that could reduce risk in prison and when individuals return to the community.

– Liviana Calzavara & Ann Burchell

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Funding for this project was provided by the National Health Research Development Program (NHRDP), Health Canada.

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[1] LM Calzavara et al. Reducing volunteer bias: using left-over specimens to estimate rates of HIV infection among inmates in Ontario, Canada. *AIDS* 1995; 9:631-637; Correctional Services Canada. *Basic Facts about Corrections in Canada 1991*. Ottawa: Correctional Services Canada, 1991; C Hankins et al. Prior risk for HIV infection and current risk behaviours among incarcerated men and women in medium-security correctional institutions – Montreal. *Canadian Journal of Infectious Diseases* 1995; 6(suppl B): 31B; M Millson et al. Prevalence of HIV infection and associated risk behaviours among injection drug users in Toronto. *Canadian Journal of Public Health* 1995; 86(3): 176-180; Ministry of Correctional Services. *Ministry of Correctional Services: Annual Report 1991*. Toronto: Ministry of Correctional Services Communications Branch, Ontario, 1991; DA Rothon, RG Mathias, MT Schecter. Prevalence of HIV infection in provincial prisons in British Columbia. *Canadian Medical Association Journal* 1994; 151(6):781-787; A Toepell Riesch. *Knowledge, Attitude and Behaviour: A Research Study of Inmates in the Toronto Region*. Toronto: John Howard Society of Metropolitan Toronto, 1992.

[2] LM Calzavara et al. *Understanding HIV-Related Risk Behaviour in Prisons: The Inmates' Perspective*. Toronto: HIV Social, Behavioural, and Epidemiological Studies Unit, 1997. ISBN 0-7727-8709-3.

Prisoner Settles Case for Right to Start Methadone in Prison

In July 1999, Dwight Lowe, an inmate at Kent Institution previously using heroin, settled his case against Correctional Service Canada (CSC) in which he challenged as unconstitutional CSC's refusal to permit him to initiate methadone maintenance treatment while in prison.[1]

On 1 December 1997, CSC announced that it would provide methadone to prisoners *who had already started this treatment before being incarcerated*,[2] a measure that was implemented in April 1998. Lowe had used heroin previously, but had not started methadone maintenance treatment (MMT) before being imprisoned.

In order to avoid sharing injection equipment to inject heroin, he applied to start MMT, but his request was denied. He started legal proceedings in the Federal Court of Canada, alleging this refusal infringed the *Canadian Charter of Rights and Freedoms* by violating his "right to life, liberty and security of the person" (s 7) and his right to "equal protection and benefit of the law"

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(s 15). His case was to be heard in mid June 1999 but was settled before the hearing.

In early 1999, CSC had changed its policy to permit inmates in "exceptional circumstances" to begin MMT in prison even if they had not previously been receiving it before incarceration.[3] And even before the adoption of this policy, at the time of the feared outbreak of HIV and hepatitis C at Joyceville Penitentiary,[4] some inmates had been allowed to begin MMT in prison. It is now expected that CSC will announce in early 2000 that its MMT program will be extended to allow opiate-dependent prisoners who were not on MMT prior to incarceration to start it in prison, not just in "exceptional circumstances," but as part of the treatment options for dependent prisoners – as has been widely recommended since the early 1990s.[5]

For more information on MMT in prisons, see info sheet 7 in the series of info sheets on HIV/AIDS in prisons produced by the Canadian HIV/AIDS Legal Network (Prevention and Treatment: Methadone. The Network: Montréal, 1999).

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[1] C Sankar. Prisoner wins right to methadone treatment. *Vancouver Sun*, 19 July 1999: B7.

[2] See R Jürgens. Methadone, but no needle exchange pilot in federal prisons. *Canadian HIV/AIDS Policy & Law Newsletter* 1997/98; 3(4)/4(1): 26-27.

[3] Correctional Service Canada. Memorandum: Amendment Interim Instruction (29-7-98): National Methadone Maintenance Treatment (MMT) Program (CD 821), 12 March 1999.

[4] See PM Ford et al. HIV and hep C seroprevalence and associated risk behaviours in a Canadian prison. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(2/3): 52-54.

[5] See, eg, recommendation 5.4 in *HIV/AIDS in Prisons: Final Report*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1996, at 109; *HIV, AIDS, and Injection Drug Use: A National Action Plan*. Ottawa: Canadian Centre on Substance Abuse and Canadian Public Health Association, 1997, at 15.

HIV/AIDS and Children's Rights

cont'd from page 1

A Universal Framework for Children's Rights

The United Nations Convention on the Rights of the Child (UNRC) was unanimously adopted by the General Assembly of the United Nations on 20 November 1989. The Convention has since been ratified by 191 member states of the United Nations and has entered into force as an international treaty. Only the United States and Somalia have not yet ratified it. This near-universal ratification establishes the UNCRC as the global standard for children's rights. The UNCRC covers the cultural, social, economic, and political rights of children and is guided in interpretation and implementation by four principles: non-discrimination; the best interest of the child; the maximum survival and development of the child; and consideration of children's opinions and views in matters that affect them. The rights defined in the Convention are indivisible and form a comprehensive framework for use in determining children's best interests.

Defining Children in the Context of Their Rights

The UNCRC defines children "as every human being below the age of 18 years unless, under the law applicable to the child, majority is obtained earlier." Unfortunately, most epidemiological data collection for HIV uses 14 as the cut-off age for children and labels all people above this age as adults. To avoid discriminating against any portion of the global population of children, all persons under the age of 18 should be counted and referred to as children. This means that until all-inclusive data on children becomes available, references and statistics that count children between the ages of 15 and 18 together with adults should be clearly identified as being inclusive of children.

Children Infected with HIV

According to the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO), children and young adults (ie, persons under 25 years of age) accounted for over one-third of the 33 million people living with HIV in 1998. As well, the majority of all new HIV infections in that year came from this population. Four million children under the age of 15 contracted HIV since the epidemic began, most of whom (about 90 percent) became infected from their mothers during pregnancy, labour, birth, or breast-feeding. In 1998 alone, it is estimated that there were 590,000 new infections among children under the age of 15, and 2.5 million new infections among children and youth in the 15-24 age group. Combined, this translates into 8500 new infections among children and young people every day.

Children Orphaned Due to AIDS

Children who became orphans due to the death of one or both parents from HIV/AIDS are a rapidly growing population in urgent need of attention. By the year 2010, the number of orphaned children is expected to reach 40 million. Current estimates from UNAIDS reveal that by 1997 a total of 8.2 million children under age 15 had lost their mothers since the beginning of the epidemic, and that in 1997 there were 6.2 million children alive who had been orphaned by HIV/AIDS. Ninety percent of these children were in sub-Saharan Africa. The need for homes and guardians for large numbers of orphans is impacting entire communities and regions of the world. A study by the Zambian Ministry of Health indicated that 40 percent of all households have one or more orphans. In Zimbabwe, eight percent of all children under the age of 15 have lost their mothers to AIDS.

Children Affected by HIV/AIDS

Children are affected by HIV/AIDS not only through infection or the loss of a parent. For example, many children experience a premature end to their childhood as they are required to become heads of households, drop out of school, work, raise younger siblings, and care for parents and other family members sick from AIDS. Furthermore, children experience greater poverty as a result of the loss due to AIDS of adult wage earners, farmers, and other skilled and contributing household members. These losses affect all of the children in a household and, where infection rates are high, entire communities. Without adequate care and support, children experience losses in health, nutrition, education, affection, security, and protection. They suffer emotionally from rejection, discrimination, fear, loneliness, and depression.

The United Nations Convention on the Rights of the Child has been ratified by 191 member states of the United Nations. Only the United States and Somalia have not yet ratified it.

The Effect of HIV/AIDS on Children's Rights

The realization of the survival and developmental rights of children, as defined in the UNCRC, are affected in obvious ways as family and community resources become strained and overburdened by HIV/AIDS. Accomplishments in child survival that were made over the past two decades are endangered. If the AIDS epidemic is not contained, the mortality rates of infants in some countries could increase by 75 percent, and those of children under five years of age by 100 percent (UNAIDS). In the absence of caring adults to protect them, and as they struggle to survive, children who experience increased poverty, abandonment, rejection or discrimination, or an added burden of responsibility for themselves and other family members, are at increased risk for abuse and exploitation. Children's rights are ignored as family property is taken, siblings are separated, the children suffer physical and sexual abuse, or the children become homeless. Girls marry at very young ages in order to have a home. Children join the 100 million children estimated to be living and working on the streets of the world (UNAIDS) or the more than one million children annually who are sexually exploited for the first time (1996 World Congress Against Sexual Exploitation of Children).

The Effect of Implementing the UNCRC on the AIDS Epidemic

Actions that support the protection of children's rights and the implementation of the UNCRC are synonymous with those that reduce the likelihood of infection with HIV. When their rights to survival, development, protection, and participation are realized, children are less likely to find themselves in situations involving a high risk of HIV infection. Protecting children from situations where they are known to be at risk of sexual abuse and exploitation, and where intravenous drug use is common, directly reduces their risk of infection. Healthy physical and emotional growth and development, access to information about their rights and about sexual health, and a voice in making decisions that affect them – all among the rights of children – are vital steps that, if begun in childhood, enable people throughout their lives to protect themselves from HIV. Lasting solutions for the next generation must address both protection from HIV and protection of children's rights.

Resources

The following are suggested Internet sites and publications where detailed information on children's rights, the United Nations Convention on the Rights of the Child (UNCRC), and the impact of HIV/AIDS on children can be found.

Internet Sites

CRIN, Children's Rights Information Network, <www.crin.org>
The website of this global network contains documents and reports from a variety of sources on numerous children's rights policies, programs, issues, and reference lists, and on the ongoing process to implement the UNCRC. The full text of and guides to the UNCRC can be accessed from this home page or directly at <www.crin.org/crc/crguides.htm>. Full texts of the policy and briefing papers presented by United Nations agencies and NGOs at the 1998 Discussion Day of the United Nations Committee on the Rights of the Child, entitled "The Rights of Children Living in a World with HIV/AIDS," are also available through this home page or directly at <www.crin.org/HIV.htm>.

Kids Connect, <www.kidsconnect.org>
This site is designed to provide a secure, interactive environment for children, especially those infected and affected by HIV/AIDS, where they can have fun, express their thoughts and concerns, and find accurate and appropriate answers to their questions about HIV/AIDS. This project is managed by professional staff from the François-Xavier Bagnoud Center (FXB) at the University of Medicine & Dentistry of New Jersey. Direct links from this site lead to an array of information resources for parents and other adults, including caregivers, researchers, and health-care professionals.

UNAIDS World AIDS Campaign 1999, <www.unaids.org>
The 1999 campaign highlighted communication with and among children, young people, and adults as a positive step toward protection from HIV/AIDS and protection of rights. Documents available on this site include: the campaign launch, "Listen, Learn, Live! Challenges for Latin America and the Caribbean," "Facts and Figures," and briefing papers on children and HIV and young people and HIV, updated for the 1999 campaign.

Documents

Aggleton, Peter and Rivers, Kim. *Gender and the HIV Epidemic*: *Adolescent Sexuality, Gender and the HIV Epidemic*. United Nations Development Programme – HIV and Development Programme, New York, 1999. This paper describes patterns of vulnerability related to gender, sexuality and age, as well as adverse social and economic conditions, that have contributed to the current situation where more than half of all new HIV infections occur in people under the age of 25, most of whom live in developing countries. The paper not only details the inequities and other difficulties that adolescents encounter, but also discusses the abilities and accomplishments of young people, particularly when working in programs to prevent HIV infection. This paper has an extensive reference list for further reading. The full text is available at <www.undp.org/hiv/Gender/ADOLESC.html>.

Collings, Jane. *Children Living in a World with AIDS: Guidelines for Children's Participation in HIV/AIDS Programmes*. Children and AIDS International NGO Network Publication with support from UNAIDS, Geneva, 1998. This pamphlet provides a guide to facilitating the involvement of children in activities related to HIV/AIDS education, prevention, and care. It uses as its framework the rights of children as defined by the UNCRC. A printed pamphlet is available from UNAIDS. Email: <unaids@unaids.org>. The complete text is available online at <www.ped-hivaids.org/education/children_living.html>.

du Guerney, Jacques. *Rural Children Living in Farm Systems Affected by HIV/AIDS: Some Issues for the Rights of the Child on the Basis of FAO Studies in Africa*. Food and Agriculture Organization (FAO) of the United Nations, Rome, 1998. This paper calls attention to the impacted rights and specific difficulties of children living in rural farming environments who are infected or affected by HIV/AIDS. It points to the need and right of such children, who outnumber urban children in sub-Saharan Africa, where most HIV/AIDS-infected and -affected children live, to obtain recognition of their complex and varied relationships within the social and economic environment of their communities. An account of specific conditions and difficulties faced by children in farming households is provided. Questions are raised regarding the inadequate inclusion of rural children in studies and data, which can leave them invisible and lead to insufficient attention in policies, programs, and human rights guidelines. The full text is available at <www.fao.org/sd/wpdirect/wpan0026.htm>.

Hunter, Susan and Williamson, John. *Children on the Brink: Strategies to Support Children Isolated by HIV/AIDS*, produced by the Health Technical Services Project of TvT Associates and Pragma Corporation for the United States Agency for International Development, Arlington, Virginia, 1998. This is a study of the social, economic, and developmental impact of HIV/AIDS on children, especially those orphaned as a result of HIV/AIDS. The study covers 23 countries where the urban rate of infection is over or near five percent. Statistical tables map the demographic impact of the HIV/AIDS epidemic and offer estimates of the projected number of orphans for each five-year period through 2010. The text of this report is planned to be made available on the soon to be constructed "DMELLED" website. Watch for this new website. For information or a printed copy, contact Lilliana Favanco at DMELLED. Tel: 703 516-9166. Email: <tvt@Tvtyassoc.com>.

Lyons, Miriam. *The Impact of HIV/AIDS on Children, Families and Communities: Risks and Realities of Childhood During the HIV Epidemic*. United Nations Development Programme – HIV and Development Programme, New York, 1998. This paper discusses the impact of HIV/AIDS on childhood, especially for children living in environments where infection rates are high or disregard for children's rights is common. Failure to respect children's rights – especially through neglect; abuse; exploitation; lack of access to education, health care, or information; or failure to provide children with an appropriate voice in decision-making – are described as part of a cycle where the growth of opportunities for abuse of children's rights and for infection with HIV are mutually enabling. The full text is available at <www.undp.org/hiv/issue30E.html>.

Joint United Nations Programme on HIV/AIDS (UNAIDS). *Fact Sheet: AIDS in Africa*. UNAIDS, Johannesburg, 30 November 1998. This fact sheet provides information about the impact of the epidemic, with specific attention to the situation for young people, orphans, and girls. Available online at <www.unaids.org>.

United Nations Children's Fund (UNICEF). *The State of the World's Children 1998*. UNICEF, New York, 1998. This report, published annually by UNICEF, includes economic and social statistical tables related to children. The tables present by-country data on topics including basic indicators, nutrition, health, education, the economy, and women's issues. The report provides a broad view of the state of the well-being of children around the globe and a glimpse of the context in which children who are infected or affected by HIV/AIDS live. Available online at <www.unicef.org/sowc98>.

For more information, contact the Interagency Coalition on AIDS and Development (ICAD) at (613) 788-5107 or <info@icad-cisd.com>, or consult their website: <www.icad-cisd.com>.

COMMUNITY-BASED RESEARCH

Ethical Review in Community-Based HIV/AIDS Research

AIDS Vancouver recently released a report on ethical review in community-based research. The report identifies some barriers facing community-based researchers and makes recommendations for facilitating this area of HIV/AIDS research in Canada. The following summary of the report was provided by its author.[1]

Background

The new Canadian Strategy on HIV/AIDS (CSHA), released in 1998, contained for the first time a specific allocation for community-based research (CBR) of $1.8 million, $800,000 of which is reserved for community-based HIV/AIDS research on and by Aboriginal people. Organizations that can apply for funding to undertake CBR must be able to administer a process for ethical review that is consistent with the recent Tri-Council Policy Statement on *Ethical Conduct for Research Involving Humans*, which articulates national standards for Canadian researchers.[2] However, most community-based HIV/AIDS organizations don't have mechanisms for research ethics review. Consequently, community-based researchers experience difficulties in accessing ethical review, and this diminishes opportunities to access the annual allocation of CSHA funding for CBR. Ultimately, this has implications for the completion of important research projects and the ethical soundness of community-based research projects. Earlier in 1999, the National Health Research Development Program (NHRDP) identified access to ethical review as a "programmatic concern" for CBR.

What Is Community-Based Research?

Community-based research is distinguished from traditional academic research in that it takes place in community settings and involves community members in the design and implementation of research projects. CBR involves collaboration with grassroots organizations and groups that have minimal claim to expertise in the "science" of research. The community, rather than the academic researcher, often defines research questions. Academic rigour may not be a dominant consideration in CBR, but the methodologies, findings, and results of CBR can have an important bearing on subsequent academic inquiry.[3]

Lack of Access to Ethics Review Committees: A Systemic Barrier

Ethical conduct in research requires that the rights of research participants be considered and respected. A primary function of an ethics review committee is to ensure that researchers design studies that conform to recognized standards of ethical conduct in research. The general principles articulated in the Canadian Tri-Council Policy Statement include: respect for human dignity; respect for free and informed consent; respect for vulnerable persons; respect for justice and inclusiveness; balancing harms and benefits; minimizing harm; and maximizing benefit.

To learn about the experiences of AIDS service organizations (ASOs) and community-based researchers with regard to the CBR initiative under the CSHA, 21 open-ended interviews were conducted nationally with ASO leaders and community researchers. Informants were asked about their experiences in applying for and accessing ethical review for CBR.

Although research ethics committees are common features of academic and clinical research institutions, they usually provide services only to their own members, so non-affiliated community-based researchers are usually ineligible. To overcome this barrier, the current strategy of community-based researchers is to rely on partnerships with academic researchers.

In such academic-community partnerships, however, the process of applying for ethical review is left to the dominion of the academic's institutional guidelines. These institutional guidelines and the members of academic ethics committees are not necessarily sensitive to ethical issues arising from CBR methodologies, nor do they provide a forum for ethical guidance and consultation for community-based researchers. Additionally, informants criticized academic ethics committees for lengthy delays in the review process, for concerns about legal liability superseding ethical responsibility, and for imposing dominant scientific-research values on community-based researchers.

In AIDS prevention research there is often a very close relationship between the affected communities and behavioural researchers. These complex relationships present challenges for institutional guidelines, which often do not understand or recognize collaborative research relationships. For that matter, members of institutional ethics committees are likely to come from research backgrounds that have placed them in control of the research process, because of scientific and funding criteria. In the context of CBR, an ethics committee needs to be aware of the distribution of power between community-based researchers and the organizations in which they work.

Conclusions

Community-based organizations and investigators recognize and respect the need for ethical conduct in research. However, obtaining ethical review for CBR projects from traditional institutional committees requires partnerships that they feel are not necessarily helpful to, or understanding of, community research goals.

One way to resolve the existing systemic barrier to ethical review for CBR would be through the establishment of competent and impartial community ethics committees. They should be understanding of the sensitive issues that often accompany HIV/AIDS projects as well as the multidisciplinary nature of CBR. The development of a community-based research ethics infrastructure would also promote increased independence for non-academic researchers and improve their awareness of ethical issues. Other potential benefits of CBR ethics committees would be:

- Community ownership of the ethics review process would promote independence in CBR. It would also help develop expertise essential to more balanced relationships with academic partners in research.
- Expedited ethics review at the community level would facilitate timely completion of research.
- Community-based ethics committees would provide direct guidance and consultation to community-based researchers and research populations.
- Community members would become more receptive to CBR as a result of increased peer involvement in the ethics review process.
- The autonomy of community-based ethics review would promote understanding of less traditional research methodologies. The ethics review process undertaken by community ethics committees can be expected to be less rigid and formulaic than academic or clinically based ethics committees.

Recommendations

1. A CBR ethics committee should be established as quickly as possible to remove the systemic barrier facing community-based researchers. The committee should be recognized as having the authority to review, approve, or reject research proposals as well as perform a positive function by providing ethical guidance to researchers and organizations.
2. The CBR ethics committee should promote principles of fairness and access, so that any CBR project in Canada could benefit from ethical review and guidance.
3. The existence of any CBR ethics committee should be made known to researchers and community-based organizations. This could be achieved by including contact information in the NHRDP grant applications.

– Russel Ogden

Russel Ogden is a consultant in Vancouver. His 1994 MA research at Simon Fraser University investigated underground practices of assisted death. In response to a subpoena issued in a coroner's inquest, he successfully defended the confidentiality of his research participants, establishing a common law precedent in Canada regarding academic privilege. Russel can be reached at <rdogden@axion.net>.

For a copy of the report summarized in this article, contact AIDS Vancouver at (604) 681-2122 or <av@parc.org>.

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[1] R Ogden. Report on Research Ethics Review in Community-Based HIV/AIDS Research. Vancouver: AIDS Vancouver, 1999.

[2] Medical Research Council, Natural Sciences and Engineering Research Council, and Social Sciences and Humanities Research Council, August 1998. The full text is available at <http://ncehr.medical.org/english/mstr_frm.html>.

[3] For further discussion, see: D Allman, T Myers, R Cockerill. Concepts, Definitions and Models for Community-Based HIV Prevention Research in Canada. Toronto: University of Toronto, 1997; T Trussler, R Marchand. Knowledge from Action: Community-Based Research in Canada's HIV Strategy. AIDS Vancouver & Health Canada, 1998.

LEGAL CLINICS

The University of Ottawa Community Legal Clinic

This is the third in a series of articles about legal clinics that provide specialized services to people with HIV/AIDS. In previous issues of the *Newsletter*, Ruth Carey provided an overview of the work of the HIV & AIDS Legal Clinic (Ontario)(HALCO),[1] and Johanne Leroux described the work of the legal clinic of the Québec Committee for people with HIV in Montréal.[2] In this article, Jennifer Duff, a law student and caseworker at the University of Ottawa Community Legal Clinic, describes the work of the HIV Legal Services division of the Ottawa Clinic.

The Legal Clinic

The University of Ottawa Community Legal Clinic (UOCLC) is an organization that provides legal services to the Ottawa-Carleton community consisting of summary legal information, legal representation, referrals, public legal education, advocacy, and law reform. The Clinic provides services for and on behalf of people of modest income, students, and historically disadvantaged groups. We are part of Legal Aid – Ontario and are affiliated with the Faculty of Law at the University of Ottawa. Services are provided by law students who are supervised by staff lawyers. Clients, courts, and the public thus can and have the right to expect the same professional conduct from a student as from a lawyer of the Bar. As an organization composed of law students, administrative staff, and lawyers, the Clinic provides its services on a cost-recovery basis in both official languages and is mandated to handle a wide variety of legal matters.

Legal Services Offered

The Clinic offers services in landlord and tenant matters, focusing on tenant representation, and we participate in a Tenant Duty Counsel Program. We also deal with criminal matters (summary infractions), quasi-criminal matters, and provincial offences (for example, involving the *Highway Traffic Act*). The Clinic also helps clients with civil matters, including information sessions on Small Claims Court proceedings, and human rights issues (for example, violations of the *Ontario Human Rights Code* and the *Canadian Human Rights Act*). The Clinic gives community legal education presentations, provides legal information and assistance addressed to the needs and concerns of Aboriginal people in the community, and supplies legal information and advocacy for women who have been or are in abusive situations. In addition, the UOCLC provides legal information and assistance for people in the community who have been diagnosed as being HIV-positive. This particular service is provided through a satellite clinic at the AIDS Committee of Ottawa.

Carleton Legal Services

New in 1999 is the Carleton Legal Clinic, a fixed satellite office at Carleton University. Its permanency was ensured following the 1999 Carleton University referendum. As a result of the referendum, Carleton undergraduates agreed to pay a direct levy toward the establishment of a legal clinic to address their needs. The Carleton Clinic's mandate is to provide legal representation and advice to Carleton students and members of the neighbouring community. The services offered are based on the case criteria of the UOCLC.

HIV Legal Services

HIV Legal Services is a division of the OUCLC and is located at the AIDS Committee of Ottawa (ACO). The division was established in 1989 when the board of the ACO approached the Clinic for help in addressing the legal needs of people with HIV/AIDS. As a joint project between the two organizations, HIV Legal Services provides access to free legal assistance and information. Its objective is to eliminate the barriers that prevent those with HIV and AIDS from exercising their legal options. The division provides issue-sensitive legal services to the ACO's client base and in so doing furthers the interests of people with HIV/AIDS. The division is committed to empowering those with HIV/AIDS as well as developing an awareness of their legal rights within the community.

While the HIV Legal Services division has case criteria that cover a diverse range of subject matters, students and Review Counsel will also consider acting for those who face a barrier in accessing the legal system (for example, visual, mental, cultural, and language barriers) even if they do not meet the usual criteria, depending on the nature of the case. For example, the division has worked on a unique case with Chantal Tie, a lawyer and executive director of the South Ottawa Community Legal Clinic, which involves an application for landing on humanitarian and compassionate grounds. The division more generally offers assistance and representation regarding matters such as filing a human rights complaint, making a complaint against the police, applications to the Criminal Injuries Compensation Board, or making a complaint against a physician or other professional. We also represent clients with employment problems, landlord and tenant issues, harassment, issues arising from the breach of confidentiality, and criminal matters. In addition, the division provides assistance by drafting wills, living wills, and powers of attorney for clients, and by providing legal information and lawyer referrals.

Recently, HIV Legal Services has expanded its case criteria to include the representation of clients in appeal procedures related to the *Ontario Disability Support Program Act.*

Issues Confronting the UOCLC HIV Legal Services Division

The wide range of legal issues covered by the UOCLC creates a variety of resource problems, including time, labour, and funding. The demand arising from the Ottawa-Carleton community is significant, and the Clinic currently has 557 files opened. Of the Clinic's total caseload, the HIV Legal Services division currently has approximately 40 active files. In addition, the division has provided legal information or referrals to several clients this year. In response to this demand, the summer of 1999 saw the division employ two law students for the first time in two years, allowing it to guarantee stronger accessibility to services by offering twelve hours of intake clinics per week. In an effort to further increase the accessibility of legal services to the community, the division has been working to develop a second satellite office at OASIS, a local drop-in centre providing a number of services to people with HIV/AIDS. Furthermore, the fall of 1999 will welcome one of the largest HIV Legal Services teams to date, with four students acting as caseworkers. Clearly, the UOCLC has demonstrated a firm commitment to increasing its provision of services to people in the Ottawa-Carleton region with HIV/AIDS, despite its limited resources.

The Ontario Legal Aid Plan funds most of the Clinic's legal services, comprising approximately two-thirds of its total budget. The Clinic was traditionally funded in part by the student governments of the University of Ottawa and Carleton University. Some years ago, these government bodies decided not to renew our funding, and as a result the survival of the Clinic was put into financial peril. In response to this crisis, a referendum was held in 1998 among the undergraduate students of the University of Ottawa and Carleton University. The student population overwhelmingly voted to have a $4.50 levy added to their tuition; this will be forwarded directly to the Clinic and its new satellite office at Carleton University. As a result of the referendum vote, the student levy will now comprise approximately one-third of the Clinic's annual budget. This additional funding has allowed the Clinic to hire an additional part-time lawyer to supervise students, as well as supplementary part-time administrative employees.

The HIV Legal Services division is funded jointly by the AIDS Committee of Ottawa and the UOCLC. Labour is provided by the University in the form of students who are hired or chosen from the Common Law program at the University's Faculty of Law. Most routine costs, such as photocopying and office supplies, are paid for by the AIDS Committee of Ottawa. This allows the division to provide entirely free legal services to people with HIV/AIDS throughout the Ottawa-Carleton community. The division also functions on a small independent budget, which is predominantly made up of funds collected from the annual AIDS Walk and from a Positive Law Conference put together by HIV Legal Services every second year. This money goes toward covering any additional expenses incurred throughout the year, such as the cost of attending conferences and out-of-town meetings, or the cost of any supplementary office equipment. As a result, the division has been able to continue providing services to the community – be it from the perspective of individual clients, the broader community, or on the national level.

Trends in Legal Issues

The HIV Legal Services division has maintained a strong commitment to providing legal services that cover a complex range of subject matters. The casework is diverse, since our clients experience a wide variety of legal problems.

Social Assistance for Medical Reasons

One of the major trends that has recently emerged involves our clients and the *Ontario Disability Support Program Act*. A person's HIV-positive status is no longer a guarantee of acceptance with respect to ODSP benefits. On the contrary, we are seeing an increasing number of clients being refused ODSP benefits after a finding that they have not demonstrated a substantial functional restriction in the workplace, in the home, and in the community. We have also been approached by clients whose ODSP payments have been canceled after a finding of a spousal relationship. These findings have been made despite the fact that clients have stated that the person they are living with is a caregiver, and that no spousal relationship exists. As a result, we have begun opening files for these clients in order to appeal the decisions to the Social Benefits Tribunal or the Social Assistance Review Board. While these files are still in their early stages, the initial results are somewhat encouraging, since the Tribunal has been willing to grant interim assistance while the appeal hearing is pending.

Tenant Issues

Another significant trend involves housing, and is likely related to the difficulty that our clients face in obtaining adequate social assistance. Landlord and tenant issues are commonplace in our Clinic, with eviction matters being the most predominant. In the past few months, HIV Legal Services has seen several tenants being evicted from their dwellings because of their inability to make monthly rent payments. Clients who are removed from ODSP and who obtain financial assistance through *Ontario Works* see their income fall dramatically, and are no longer able to pay for basic necessities. Often, the best option available is to delay the eviction until the client is able to find less expensive yet adequate housing, so that they are not left homeless, since homelessness often brings with it the increased risk of developing infections and accelerating the progression of HIV.

Inadequate Care

Finally, many clients have received inadequate care at the hands of medical professionals. While our student status and limited resources do not allow us to pursue medical malpractice litigation, we commonly make complaints to the College of Physicians and Surgeons of Ontario. Medical complaints have arisen from issues surrounding confidentiality, testing, and unethical treatment. The remedies in this forum are limited to a doctor being disciplined, and no financial compensation is awarded to the client. However, at the very least, a doctor may genuinely apologize for their actions, which can bring some resolution to the situation. In addition, the division recently successfully carried out a Complaint Review hearing before the Health Professions Appeal and Review Board.

Conclusion

The University of Ottawa Community Legal Clinic is committed to providing people with HIV/AIDS with professional, competent, and caring legal representation and information. While the problems faced by our clients are diverse and complex, we are attempting to answer this great need by increasing the size of the HIV Legal Services division, as well as expanding our case criteria to better meet the needs of the Ottawa-Carleton community. Although the Clinic continues to face financial constraints, through the dedication and commitment of its students, lawyers, and staff, we are encouraged by our growth and especially by the tenacity of our clients, who are willing to fight for their rights and for justice.

– Jennifer M Duff

Jennifer M Duff is a law student and a caseworker at the HIV Legal Services division of the University of Ottawa Community Legal Clinic. She can be reached at ianjenn.duff@sympatico.ca. For more info about the HIV Legal Services division, call (613) 562-5600; fax (613) 562-5602; website: <www.uottawa.ca/associations/clinic>.

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[1] R Carey. Provision of legal services to persons with HIV or AIDS: barriers and trends. *Canadian HIV/AIDS Policy & Law Newsletter* 1997/98; 3(4)/4(1): 9-11.

[2] J Leroux. The Montréal legal clinic for people with HIV/AIDS. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(2/3): 15-17.

CRIMINAL JUSTICE

Criminal Law and HIV/AIDS: Update II

This article reviews new developments in the area of criminal prosecutions for HIV transmission or exposure, or developments that have come to our attention since the last issue of the Newsletter.[1] This column will continue to be a regular feature. However, we will not continue to report cases or legislation from jurisdictions other than Canada *unless they represent a significant development*, either in this area of the law or for the jurisdiction in question.

Canada

In June 1999, an HIV-positive Toronto man was charged with two counts of attempted murder for allegedly spitting in the faces of two police officers in Trois-Rivières. Media reports stated the man was arrested after a car accident and was being escorted to hospital when, according to police, he bit the inside of his mouth and spat at the officers, hitting both of them in the eyes with bloody saliva. He was also charged with two counts each of aggravated assault and uttering death threats. During his subsequent court appearances, police shackled his wrists and ankles, covered his head with a hood, and taped his mouth shut. At his court appearance, he denied being HIV-positive or spitting at the officers, alleging the blood came from his nose, which had been broken by officers during the arrest.[2]

In July 1999, a Newfoundland man was charged with four counts of aggravated assault, three counts of common nuisance, one count of sexual assault, and one count of uttering threats, for allegedly having unprotected sex with four women without disclosing his HIV-positive status. He was released from custody on strict conditions pending his next appearance to enter a plea.[3]

In September 1999, a Newfoundland man imprisoned for engaging in unprotected sex without disclosing his HIV-positive status was denied parole. Raymond Mercer pleaded guilty in 1992 to two counts of criminal negligence causing bodily harm, and was sentenced to over 11 years in prison. Parole officials were reported as saying that they believe he is at risk of re-offending.[4]

Australia

Early in 1999, a 30-year-old HIV-positive man in the state of Western Australia pleaded guilty to one charge of having a sexual relationship with a minor under 16; the consensual relationship had lasted from 1994 to 1996. He was also found guilty of infecting the youth with HIV. He was sentenced to 10 years' imprisonment, with no possibility of parole for six years. Williams J of the District Court ruled he was satisfied beyond reasonable doubt that Dwayne Roland had transmitted HIV to the youth, stating that the legal standard of proof was different from the scientific standard. Evidence at the hearing indicated that the youth had casual encounters with other men, including unprotected anal sex with one of those other men. An expert testified that the evidence suggested the youth contracted HIV from Rowland, although this could not be proved conclusively.[5]

In March, a 44-year-old Sydney man was charged with attempting to transmit a grievous bodily disease under the *Crimes Act* of the state of New South Wales. Section 36 of the statute states that a person who maliciously causes, or attempts to cause, another person to contract a grievous bodily disease is liable to imprisonment for up to 25 years.[6]

New Zealand

In April 1999, Christopher Truscott, a 31-year-old HIV-positive gay man with an intellectual disability, was arrested in Christchurch and charged with criminal nuisance for having unprotected sex without disclosing his serostatus. At the time of publication, he was awaiting trial, after having pleaded not guilty. In the interim, he has been detained under New Zealand's *Health Act* (s 79), which grants a medical officer of health the power to detain and isolate a person with an infectious condition when the officer has grounds to believe they could be communicating the disease.[7]

In May 1999, a second HIV-positive gay man, Richard Burley, was also charged with criminal nuisance for having unprotected sex with another man without disclosing his serostatus. He pleaded guilty in July 1999, and was given a suspended sentence. He was subsequently isolated in the same house as Truscott, under the same provision of the *Health Act*.[8]

In August 1999, an HIV-positive man who had unprotected sex with his girlfriend without disclosing his serostatus pleaded guilty to a charge of criminal nuisance and received a sentence of nine months' imprisonment.[9]

United States

Arkansas

In May 1999, the Arkansas Court of Appeals upheld the use of a prosecutor's subpoena to obtain public health documents for the purpose of investigating a man suspected of transmitting HIV to a female partner.[10] Pierre Weaver tested HIV antibody–positive through a partner notification program undertaken by public health authorities. At that time, he was counseled that Arkansas law required him to disclose his HIV-positive status to partners before engaging in sexual intercourse. He subsequently had unprotected sex with a woman who later tested HIV-positive. As permitted under state law for investigatory purposes, the prosecutor issued a subpoena to obtain the public health department's records about Weaver's infection. The trial judge permitted these records to be introduced in evidence at Weaver's trial. On appeal, Weaver argued the police did not procure a valid search warrant, meaning the records were illegally obtained and should have been excluded from evidence. However, the appeals court ruled that the prosecutor did not abuse the power to issue a subpoena for investigative purposes by having a police officer serve the subpoena and seize the records; in the court's view, the police officer was merely acting as a courier. The appeals court also noted that Weaver did not object at trial when these records were introduced as evidence.

Idaho

In July 1999, the Idaho Court of Appeals confirmed a jury's felony conviction of Kerry Thomas in April 1997 for transferring body fluids which may contain HIV, and confirmed his sentence of 15 years in prison, seven of them with no possibility of parole.[11] Thomas had tested HIV-positive in 1990. He met the complainant, a pre-operative transsexual, in a bar in April 1996. The complainant testified that they discussed her transsexuality over drinks before returning to her apartment, where they engaged in unprotected oral and anal sex (without Thomas ejaculating). According to the complainant, Thomas did not tell her of his HIV status before or after sex. The next morning, one of her roommates told her of rumours that Thomas was HIV-positive.

Under Idaho's "criminal exposure" statute (IC § 39-608), Thomas could not be convicted if there was reason to believe that the complainant had consented to the risk. He did not testify at the trial, but sought to undermine the complainant's credibility, arguing that she had had several alcoholic drinks, that she practises deception by dressing as a woman despite being biologically male, that she suffers from bipolar disorder and misuses substances, and that she has a reputation for untruthfulness and melodrama. The appellate court indicated two possible defences existed to the charges: either there had been full disclosure preceding the sexual activity, or the transfer of bodily fluids had occurred after Thomas had been advised by a physician that he was not infectious. In the court's view, there was "substantial and competent evidence" (from both the complainant and her roommates) to support the jury's guilty verdict. The court also upheld the sentence as reasonable, given Thomas's previous conviction in 1990 for statutory rape for another encounter in which he did not inform his female partner of his HIV-positive status.

Indiana

In February 1999, John Martin, a 39-year-old HIV-positive Indianapolis man, was sentenced to six months' imprisonment for engaging in unprotected sex with his ex-girlfriend. He was convicted of the offence of "failure to warn a person at risk," a misdemeanour under Indiana law. After pleading guilty, he received the maximum sentence. The woman was reported to have tested HIV-negative.[12] In May 1999, he pleaded guilty in another county to two additional felony charges of criminal recklessness, again for unprotected sex with two other women, neither of whom were infected. He was sentenced to one year in a work-release facility and one years' probation, as well as 100 hours of community service and a $3355 fine. (The maximum sentence was three years' imprisonment and a $10,000 fine.) One of the women has filed a civil suit against Martin.[13]

Michigan

In June 1999, an HIV-positive man was sentenced to four to six years in prison after pleading guilty to two counts of failing to disclose his serostatus to his sexual partner. David Brown was diagnosed HIV-positive in 1988. Starting in late 1998, for roughly three months he had a sexual relationship with a woman that included sex up to five times a week over that period. She discovered he was HIV-positive upon opening a letter to him from an AIDS service organization, while he was being held in jail on charges of domestic violence.[14]

Mississippi

In February 1999, the Judiciary Committee of the state Senate refused to move forward with two "criminal exposure" bills. The first bill, SB 2206, would have made it a felony for anyone, knowing they are HIV-positive, to have sex or share needles without obtaining their partner's consent to the exposure. The second bill, SB 2450, would have required the prosecution to prove that someone accused of the felony of criminal exposure acted either with malicious intent or with reckless disregard of the possibility of exposure. Both bills would have enacted sentences of three to six years' imprisonment upon conviction.[15]

New Hampshire

In the state's first case of this kind, New Hampshire pursued a criminal prosecution against a 28-year-old HIV-positive man for having unprotected sex. Angel Cabrera pleaded guilty to three counts of reckless conduct and three counts of statutory rape, for sexual encounters with a 14-year-old girl in late 1997 and early 1998. The judge imposed the maximum sentence pursuant to the plea agreement: two consecutive sentences of three-and-a half to seven years. The definition of reckless conduct in New Hampshire law requires the use of a "deadly weapon," which is defined as "any substance or thing which, in the manner it is used, is known to be capable of producing death or serious bodily injury." In April 1998, following a motion by Cabrera, a judge ruled that a body part can be used in a manner that meets this definition. New Hampshire has no specific statute criminalizing HIV exposure.[16]

New York

As reported previously in the *Newsletter*,[17] Nushawn Williams pleaded guilty at the end of February 1999 to criminal charges for engaging in unprotected sex without disclosing his HIV-positive status. He was accused of infecting at least 13 young women with HIV through unprotected sex. He pleaded guilty to two charges of reckless endangerment in the first degree and one charge of rape in the first degree. This plea bargain was struck after only two complainants agreed to testify. He was sentenced in April 1999 to four to twelve years in prison.[18]

North Carolina

A North Carolina man convicted of raping a 12-year-old girl had his conviction affirmed by the state's Court of Appeals in February 1999. Andrew Lee Monk was convicted of first-degree rape and taking indecent liberties with a minor for the assault, which took place in his home in December 1996. He was sentenced to 35 to 42.75 years' imprisonment on the rape charge and 22 to 32 months on the indecent liberties charge. The prosecution also charged him with attempted murder and assault with a deadly weapon, based on the fact of his HIV-positive status. (The victim was not infected.) However, the prosecution dropped these charges after testimony establishing his HIV status was entered into evidence before the jury. The defence lawyer had unsuccessfully sought to have these charges severed from the rape-related charges. On appeal, Monk argued the court's refusal to sever these charges resulted in unfairly prejudicing the jury against him because of his HIV-positive status. The appellate court, however, said that evidence as to his HIV status was more probative than prejudicial; however, it failed to address why the prosecution withdrew those charges late in the trial.[19]

Ohio

In January 1999, a bill was introduced in the state House of Representatives that would make it a felony, punishable by two to eight years in prison and a fine of up to $15,000, for someone with HIV to not disclose their status to a prospective sex or needle-sharing partner. The bill, HB 100, is similar to a bill that was approved by the House in 1998 but failed to pass the state Senate.[20]

In May 1999, a state appellate court affirmed the conviction of

James Russell for the kidnap and rape of a developmentally disabled 17-year-old.[21] Evidence at trial showed that Russell convinced the victim, whom he met at a local shopping mall, to come home with him. Before this, Russell brought the youth with him to a meeting with Russell's probation officer. According to trial evidence, the officer raised Russell's HIV-positive status with him and warned him to not get involved with the youth. Subsequently, with the assistance of another man, Russell forced the youth to have sex. At trial, Russell unsuccessfully argued that the youth had consented to the sex. On appeal from his conviction, Russell argued that the trial court erred in permitting the prosecution to introduce prejudicial evidence that Russell is HIV-positive. However, the appeal court noted that Russell's status was relevant to his contention that the youth consented to the sex, as well as to Russell's intent, because of the earlier warning from the probation officer about his HIV status and involvement with the youth. The court concluded the probative value of the evidence outweighed its conceivably prejudicial effect.

In July 1999, an Ohio jury convicted Henry Couturier of "felonious assault" for exposing a 13-year-old female prostitute to HIV. The complainant was addicted to crack, and claimed that Couturier never told her of his status before any of the four occasions they had sex. She testified he wore a condom for the first three encounters but not on the fourth. She subsequently tested HIV-positive. Couturier testified he did not know her age, that he did tell her of his illness, and that he wore a condom on all occasions. Both he and the complainant agreed the sex was consensual and no money exchanged hands. Defence counsel argued there was insufficient proof that the complainant was infected by Couturier, given her sex work. Her testimony was that she always had customers use condoms, and that she had only had unprotected sex with her boyfriend, who has tested negative. The prosecution argued that HIV amounts to a "deadly weapon" and that even if the complainant had not been infected by Couturier, the offence of "felonious assault" was still made out. Couturier was convicted by a jury and sentenced by the trial judge to seven years' imprisonment. Defence counsel indicated the conviction would be appealed.[22]

Pennsylvania

In February 1999, a 39-year-old HIV-positive man was convicted and sentenced to 13.5 to 27 years in prison for biting a Wal-Mart security officer on the hand. According to testimony from the guard, he confronted Eric Rivera Perez in the store parking lot after observing him shoplifting. When security officers tried to escort Perez back into the store, he bit the first officer and yelled that he "had AIDS" and would bite them. Perez subsequently told police he had AIDS and admitted biting the guard. He consented to a blood test, which confirmed he was HIV-positive. At trial, he testified he did not recall biting the guard and did not know HIV could be transmitted through biting. The prosecutor argued this was not consistent with the evidence of his threats to the guards, and that all that had to be proved was that he placed the officer at risk of infection. (The guard was not infected.) The prosecution and defence agreed to a plea bargain of no more than 27 months' imprisonment. However, in November 1998, a judge rejected this agreement, citing Perez' long criminal record and saying that the offence was too serious. Perez was then later convicted by the jury at trial.

Tennessee

In November 1998, disc jockey William Shadwick was charged with criminally exposing two women to HIV. Following his arrest, additional complainants contacted police.[23]

In December 1998, Pamela Wiser, an HIV-positive Tennessee woman, pleaded guilty to 22 felony counts of knowingly exposing her male partners to HIV through unprotected sex, and claimed that she had up to 50 one-night stands to seek revenge for being infected with HIV by her ex-boyfriend. But in February 1999, she subsequently stated she had had sex with only 18 men. She also denied exposing them intentionally, claiming that she had informed all of them she was HIV-positive. She was eventually sentenced to 26 years in prison.

In mid July 1999, Martin Jones, a 37-year-old Knoxville man with HIV, pleaded guilty to criminal charges for exposing three women to HIV without disclosing his status. One of the women contracted HIV. He entered his guilty plea shortly before the complainants were to begin testifying.[24]

At the end of July, the Tennessee Court of Criminal Appeals reversed a four-year prison sentence imposed on a man who had unprotected sex with his girlfriend five times without disclosing his status.[25] Chester Lebron Bennett was convicted under a Tennessee statute creating the offence of "criminal exposure of another to HIV." (His girlfriend continued to test HIV-negative six months following exposure.) His girlfriend approached police with a complaint after discovering HIV medications he inadvertently left at her house. After being charged, Bennett attempted suicide twice, admitted himself to a psychiatric hospital for treatment, and subsequently received counseling from a community AIDS organization. The trial judge felt four years' imprisonment was required to deter others from similar conduct. However, after he had served 16 months of his sentence, the appellate court concluded that, for this level of offence, there is a presumption in favour of a non-custodial sentence and that the state must show a specific need for deterrence through incarceration. The court said that "it would appear unlikely [sic] that the imprisoning of an obscure indigent defendant will have little, if any, deterrent effect upon those likely to commit similar crimes in the future." The court also felt that greater regard had to be given to Bennett's efforts at rehabilitation after being charged, noting the views of the community AIDS organization that Bennett had made considerable progress and had married a woman to whom he had disclosed his HIV-positive status and criminal charges.

Virginia

In February 1999, a committee of the state Senate voted unanimously to table indefinitely a bill passed by the House to create a new offence of "infected sexual battery." The coalition Virginia Organizations Responding to AIDS had organized opposition to HB 296, which proposed a sentence of up to 12 months and a fine of up to $2500 for a first offence; a second offence would have been classified as a felony punishable by up to 10 years in prison. The coalition argued the bill would discourage HIV testing and it would be difficult to prove consent.[26]

Wisconsin

In March 1999, an HIV-positive Wisconsin man, Antonio Buford, pleaded guilty to the felony of recklessly endangering safety in the first degree, for having unprotected sex with a woman as "payback" for him having contracted the virus from another person. After the complainant (who was not infected) asked that he be treated leniently, he was given a nominal sentence of three months in jail, three months' electronic monitoring at home, and five years' probation. A violation of the terms of probation will mean an automatic three years in jail.[27]

Military justice system

In July 1999, the US Court of Appeal for the Armed Forces upheld the conviction of Brian Warden, an HIV-positive man, for having unprotected sex with a woman in violation of a military safe-sex order. The appellate court rejected his argument that the conviction be set aside because a key witness refuting his alibi was a former secretary of one of the panel rendering the judgment. The higher court noted that the panel member himself had been sensitive to the appearance of a conflict of interest, but had stated he was confident he could judge the evidence impartially.[28]

In May 1999, the US Supreme Court unanimously decided that the military has the right to dismiss an officer who had unprotected sex with two women without disclosing his HIV-positive status.[29] James Goldsmith was convicted by a court martial in 1994 of wilfully disobeying an order to disclose his status before engaging in unprotected sex. In 1988 and in 1993 he breached this order. He was sentenced to six years in prison and forfeiture of part of his monthly salary for 72 months. The Air Force then relied on 1996 legislation (enacted after his conviction) to take the administrative step of terminating his service in the military. To avoid losing access to medication through loss of employment, Goldsmith appealed. The military appeals court ruled in his favour, saying the attempted discharge amounted to a second punishment for the same offence, which is unconstitutional. However, the US Supreme Court set aside this decision, saying the appeals court was outside its jurisdiction; it could review the findings and decisions of the court martial, but not an administrative decision to terminate. The Supreme Court also ruled that, under the legislation invoked by Goldsmith, the appeals court could only provide such relief when no other method of review would suffice, but in this case Goldsmith could pursue a remedy elsewhere under statute. The Supreme Court noted that Goldsmith may have recourse to an internal Air Force tribunal, and to the federal trial courts beyond that.

Other Jurisdictions

In August 1999, the *Malawi* Law Commission confirmed it was revising the country's Penal Code and, as part of this larger review, would be holding a series of workshops on the issue of criminalizing HIV transmission to obtain wide input from the public and other interested bodies.

According to media reports, a reform officer from the Commission indicated the contemplated changes would only extend to individuals “deliberately spreading the AIDS virus.” HIV transmission will be included in legislation applying to the spread of infectious diseases generally.[30]

Also in August, the government of *Swaziland* put forward its proposed new Public Health Bill. The bill stipulates that those convicted of rape who infect a victim with HIV could face the death penalty. It also permits a penalty of life imprisonment for anyone who knowingly transmits HIV to a sexual partner, although it allows for lesser sentences in special circumstances, including provisions compelling a person convicted of transmitting the virus to provide financial compensation to those infected. A person convicted of sexually transmitting other diseases, such as syphilis, gonorrhea, or genital herpes, is subject to a maximum fine of 10,000 rand. Parliamentary debate on the bill is to follow.[31]

In *South Africa*, the Law Commission released its report with recommended changes to the law with respect to sexual offences. The Commission’s report indicates that it makes

> no proposals concerning the criminalising of harmful HIV-related behaviour and the HIV testing of persons arrested for committing sexual offences. The Commission, however, does recognise the strong public demand for the provision of HIV post-exposure prophylactic treatment to victims of sexual violence and will deal with this particular aspect in a subsequent discussion paper on process and procedural issues.[32]

– Richard Elliott

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[1] See Criminal law and HIV/AIDS: update I. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(4): 48-49. Please note that the citation to the report of the judgment from the January 1999 Court of Appeal for England & Wales case was mistakenly omitted from Update I. The citation is *R* v *Coyle*, [1999] EWJ No 149 (CA) (QL).

[2] Mouth taped, man faces attempted murder charges. [Montréal] *Gazette* 17 June 1999: A5; Man accused of attempted murder for spitting. *Canadian Press*, 16 June 1999.

[3] Man charged with infecting women. [St John’s] *Telegram* 15 July 1999: 4.

[4] Parole denied man who spread AIDS virus. [St John’s] *Telegram* 9 September 1999: 4; Liberté refusée pour un porteur du virus du sida. *L’Acadie Nouvelle* 9 September 1999: 2; Parole denied to man who spread AIDS. *Moncton Times and Transcript*, 9 September 1999: A10.

[5] Reported in [Australian] *HIV/AIDS Legal Link* 1999; 10(1): 3.

[6] Reported in [Australian] *HIV/AIDS Legal Link* 1999; 10(1): 6.

[7] Reported in [Australian] *HIV/AIDS Legal Link* 1999; 10(2): 22; B Clarke. Man’s HIV kept secret. *Sunday Star-Times*, 16 May 1999; K McNeil. Police make new arrest for HIV sex. *The Press*, 17 May 1999; HIV-positive men to be kept in isolation. *The Press*, 16 August 1999; Personal email communication from A MacDonald, New Zealand AIDS Foundation, 25 August 1999.

[8] Ibid.

[9] Ibid.

[10] *Weaver* v *Arkansas*, Ark Ct App, No CACR 98-186, decided 12 May 1999, reported in *AIDS Policy & Law* 1999; 14(11): 11.

[11] *Idaho* v *Thomas*, No 23905 (Idaho Ct App, 26 July 1999), reported in *AIDS Policy & Law* 1999; 14(15): 9-10; *Lesbian/Gay Law Notes* September 1999: 143.

[12] Reported in *AIDS Policy & Law* 1999; 14(5): 12.

[13] Reported in *AIDS Policy & Law* 1999; 14(10): 12.

[14] Reported in *AIDS Policy & Law* 1999; 14(15): 4.

[15] Reported in *AIDS Policy & Law* 1999; 14(4): 4.

[16] Reported in *AIDS Policy & Law* 1999; 14(16): 10.

[17] R Elliott. Criminal law and HIV/AIDS: new developments. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(2/3): 45-51 at 49.

[18] Prosecutor seeks new law to shield HIV exposure victims. *AIDS Policy & Law* 1999; 14(5): 8; Man who spread HIV sent to jail. *The Patriot Ledger (Quincy)*, 6 April 1999.

[19] *North Carolina* v *Monk*, NC Ct App, No COA98-277, filed 16 February 1999, reported in *AIDS Policy & Law* 1999; 14(4): 9.

[20] Reported in *AIDS Policy & Law* 1999, 14(4): 4.

[21] *State* v *Russell*, 1999 WL 236693 (22 April 1999), reported in *Lesbian/Gay Law Notes* May 1999: 82.

[22] Reported in *Lesbian/Gay Law Notes* September 1999: 147.

[23] Tennessee disc jockey charged with criminal spread of HIV. *Associated Press*, 19 November 1998.

[24] Man pleads guilty in HIV trial. *The Tennessean*, 15 July 1999.

[25] *State of Tennessee* v *Bennett*, 1999 WL 544653 (Tenn Crim App, No 03C01-9810-CR-0036, 28 July 1999) (not officially reported), reported in: *Lesbian/Gay Law Notes* September 1999: 144; *AIDS Policy & Law* 1999, 14(15): 9.

[26] Reported in *AIDS Policy & Law* 1999; 14(4): 4.

[27] Reported in *AIDS Policy & Law* 1999; 14(6): 12.

[28] *US* v *Warden*, 1999 WL 518820 (US Ct of App for the Armed Forces, 21 July), reported in *Lesbian/Gay Law Notes* September 1999: 147.

[29] *Clinton* v *Goldsmith*, US, No 98-347, 17 May 1999, reported in *AIDS Policy & Law* 1999; 14(10): 10-11; *Lesbian/Gay Law Notes* June 1999: 94-95.

[30] R Tenthani, D Langeveldt. Malawi plans to prosecute AIDS carriers. *African Eye News Service*, 5 August 1999, via Africa News Online <www.africanews.org>; R Tenthani. Malawi seeks to prosecute reckless HIV transmitters. *Panafrican News Agency*, 11 August 1999, via Africa News Online <www.africanews.org>.

[31] A Zwane, D Langeveldt. Rapists in Swaziland face the death penalty. *African Eye News Service*, 18 August 1999, via Africa news Online <www.africanews.org>.

[32] South African Law Commission. *Sexual Offences: The Substantive Law*. Discussion Paper 85, Project 107, Pretoria, 1999. See also: South African Law Commission. *Compulsory HIV Testing of Persons Arrested in Sexual Offence Cases*. Discussion Paper 84, Project 85, Pretoria, 1999. Both documents are available on the Commission’s website at <www.law.wits.ac.za/salc/salc.html>.

PUBLICATIONS REVIEWED

AIDS and Stigma in the United States[1]

In 1988, Gregory Herek and Eric Glunt described the public reaction to AIDS in the United States as an "epidemic of stigma."[2] Since then there has been a growing body of research on AIDS-related stigma in the United States. The April 1999 issue of the *American Behavioral Scientist*, edited by Herek, provides a convenient snapshot of the status of that research.[3] Many of the papers were originally presented at a workshop on AIDS-related stigma convened in 1996 by the Office on AIDS of the National Institute of Mental Health in the United States. The papers not only confirm aspects of AIDS-related stigma already noted in earlier research; they also provide insight into what contributes to AIDS-related stigma and how it might be lessened.

Studies of AIDS-related stigma distinguish between *instrumental* stigma and *symbolic* stigma.[4] Instrumental stigma refers to the fear that people have of a communicable and deadly disease. Symbolic stigma refers to the attitudes that people have about AIDS based on their attitudes toward groups associated with HIV and behaviours that transmit HIV. Recent research confirms the significant role of symbolic stigma in negative attitudes about AIDS and toward people with AIDS. Most heterosexual adults in the United States continue to associate AIDS with male homosexuality (despite changes in the demographics of the epidemic), and they respond more negatively toward a gay or bisexual man who contracted HIV sexually than a heterosexual man or woman who contracted HIV sexually. Feelings about injection drug users are even more negative than those about other people with HIV/AIDS.[5]

There are cultural variations in symbolic associations with AIDS, which reflect variations in experiences, values, and norms. While both black and white Americans associate AIDS with homosexuality, negative associations with homosexuality contribute more to AIDS-related stigma among whites, whereas negative associations with injection drug users contribute more to AIDS-related stigma among blacks.[6]

These attitudes have consequences.[7] There is evidence that the stigma associated with AIDS deters people at risk of HIV infection from seeking testing. Delayed testing, in turn, prevents people with HIV from seeking early treatment for HIV disease and counseling on reducing the risk of exposure for others. There is also evidence that the stigma associated with AIDS inhibits people with HIV from disclosing their serostatus to others. While non-disclosure deprives people of potential social support from family and friends, many who disclose have experienced rejection. Stigma may also be a reason that people with HIV – particularly those from doubly stigmatized sociodemographic groups such as street-involved drug users – delay accessing care. Moreover, stigma transfers to people associated with HIV/AIDS, such as volunteers.[8] Volunteers working with people with HIV/AIDS experience more stigma than those working with people with terminal illnesses other than AIDS. If people anticipate such stigma, they may be deterred from volunteering. If they do not anticipate such stigma and volunteer nevertheless, they are more likely to become dissatisfied and to burn out.

Symbolic associations with AIDS, which contribute so powerfully to negative attitudes toward AIDS and people with HIV/AIDS, are not easily changed. They are, as one paper argues, rooted in social identities that people protect by distinguishing "them" from "us."[9] People's emotional reactions to AIDS are an expression of the sense they have of themselves as healthy, moral, responsible, and safe people. Such reactions are a way of establishing a sense of control and invulnerability in the face of deadly disease. People may overcome their initial negative reactions when they consider the value that they themselves or others assign to non-prejudicial behaviour. But such considerations are selective. One study found that people adjusted their reactions to having lunch with a little girl with HIV but not to having lunch with a person addicted to drugs.[10] Similarly, as another study suggests, institutions that were instrumental in protecting civil rights in a previous era may not be supportive of people with HIV/AIDS because of overriding values regarding homosexuality or drug use.[11]

What can be done to change negative attitudes toward people with HIV/AIDS? One approach is to pass laws that protect people with HIV/AIDS from discrimination and breach of privacy and confidentiality. But the effect of such legislation is uncertain. On the one hand, anti-discriminatory laws help to establish egalitarian norms for public debate about attitudes toward gays, bisexuals, and drug users, which in turn can check exclusive attitudes.[12] On the other hand, it is not at all clear that people who are marginalized see the law, and law enforcement agencies, as sources of protection. Or that they are aware of the laws that protect them. Or that they are not influenced by laws that threaten them. Or that they feel entitled to protection. Or that the protections afforded by the law are relevant to them.[13]

The papers in this issue deal with the situation in the United States. The situation in Canada is different in some important respects. Canadian law includes protection against discrimination on grounds of sexual orientation, and Canadian courts have required governments to provide the same benefits to same-sex partners as to heterosexual partners of employees. Moreover, while Canadian political discourse is not free of derogatory claims about homosexuality, extreme positions based on religious beliefs have not gained widespread acceptance by political and religious institutions in most jurisdictions. But one should not overestimate the significance of these differences. While anti-discriminatory laws may establish norms for public policy with regard to sexual orientation, they do not immediately create safe environments for gay, lesbian, bisexual, and transgendered people in their homes, communities, schools, and places of work. Moreover, protective measures and behavioural norms intended to ensure provision of benefits, access to services, and quality of services are more relevant and effective for people whose rights are more readily recognized and who are in a position to defend their rights. Socially marginalized injection drug users, who constitute an increasing percentage of people with HIV in Canada, are not in this group of people.

There is room for more research.[14] In particular, there is a need for studies that document and explain the effects of AIDS-related stigma on access to HIV testing and HIV care (many of the studies reported in this issue are dated[15]). And there is a need for research to determine whether current strategies to change AIDS-related stigma or remedy its consequences are in fact effective in changing negative attitudes associated with AIDS and in supporting people who are stigmatized by those attitudes. Moreover, Canadians will need to assess to what extent research in Canada confirms the conclusions of research in the United States. But the papers in this special issue and the literature cited in them – whose findings this review can only highlight in a summary and selective manner – provide a current point of departure for further analysis, investigation, and planning.

– Theodore de Bruyn

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

[2] GM Herek, EK Glunt. An epidemic of stigma: public reactions to AIDS. *American Psychologist* 1988; 43(11): 886-891.

[3] Supra, note 1. Hereinafter referred to as Herek 1999.

[4] GM Herek. AIDS and stigma. In Herek 1999: 1106-1116 at 1110.

[5] GM Herek, JP Capitanio. AIDS stigma and sexual prejudice. In Herek 1999: 1130-1147 at 1133-1140.

[6] JP Capitanio, GM Herek. AIDS-related stigma and attitudes toward injecting drug users among black and white Americans. In Herek 1999: 1148-1161 at 1153-1156.

[7] MA Chesney, AW Smith. Critical delays in HIV testing and care: the potential role of stigma. In Herek 1999: 1162-1174.

[8] M Snyder, AM Omoto, AL Crain. Punished for their good deeds: stigmatization of AIDS volunteers. In Herek 1999: 1175-1192.

[9] PG Devine, EA Plant, K Harrison. The problem of "us" versus "them" and AIDS stigma. In Herek 1999: 1212-1228.

[10] JB Pryor, GD Reeder, S Landau. A social-psychological analysis of HIV-related stigma: a two-factor theory. In Herek 1999: 1193-1211 at 1204.

[11] MT Fullilove, RE Fullilove III. Stigma as an obstacle to AIDS action: the case of the African American community. In Herek 1999: 1117-1129.

[12] Devine et al, supra, note 9 at 1225-1226.

[13] S Burris. Studying the legal management of HIV-related stigma. In Herek 1999: 1229-1243.

[14] See GM Herek et al. Workshop report: AIDS and stigma: a conceptual framework and research agenda. *AIDS & Public Policy Journal* 1998; 13(1): 36-47 for a summary of the research agenda proposed by the workshop.

[15] Chesney & Smith, supra, note 7.

The Rights of People Who Are HIV Positive[1]

***The Rights of People Who Are HIV Positive* is subtitled "The authoritative ACLU [American Civil Liberties Union] guide to the rights of people living with HIV disease and AIDS", and, as far as I can tell, it is (authoritative, that is).**

Unfortunately, from my point of view, the book is exclusively designed for American readers. If I were an American with HIV/AIDS and living in the United States, this would not be a drawback, as *The Rights of People Who Are HIV Positive* is an excellent and detailed description of the legal information that a person with HIV/AIDS is likely to want to have at their fingertips. Better still, it is written in plain English, in an accessible style that makes for relatively easy reading. For American lawyers, it is a good primer on how HIV-related legal issues have been approached in the past, with useful endnotes containing citations to the leading cases. For those working in advocacy organizations, each chapter contains recommendations for how the law might be improved. As a Canadian lawyer familiar with HIV-related legal issues, I found it to be a fascinating lesson in difference and commonality. For days I went around the office, alternating between horror and envy, saying things like, "Did you know that in the US mandatory HIV testing of military personnel, health-care workers, firefighters, and paramedics is legal?" and "Did you know that in California an insurance company cannot require you to take an HIV test when you apply for coverage?"

The book is divided into four parts: Science and Public Health; Living with HIV Disease; Discrimination Against People with HIV Disease; and HIV Disease in Special Settings. Each part has multiple chapters. The first part contains chapters that form a sort of primer on HIV/AIDS and the law: information about HIV/AIDS as a disease; testing issues; confidentiality; public health measures; and liability for transmission. The chapter on HIV/AIDS as a disease might be of particular use for practitioners unfamiliar with HIV/AIDS or who need a handy exhibit for a tribunal whose members are in need of AIDS 101 education. The second part contains chapters that cover the issues that inform the day-to-day concerns of living and dying: health care; insurance; access to benefits; estate planning and substitute decision-making; and family law. The third part covers discrimination laws in their various settings, and the final part covers some unique and troubling issues: immigration; prisons; schools; and injection drug use. The breadth of coverage of issues here is remarkable and exactly what I would like to see in an equivalent Canadian manual for people with HIV/AIDS.

That said, I would caution Canadians with HIV/AIDS (and, generally, everyone from outside the US) from being misled by some of the information in this book. Some aspects of the law are remarkably familiar in their similarity to Canadian law: substitute decision-making and estate planning comes to mind as a good example of how similar the laws in our two countries can be. There are echoes of such similarities throughout the book, but there are also jarring incongruities with Canadian law and practice. A good example would be the chapter on liability for transmission. In the US there have been a number of cases of military personnel with HIV/AIDS being imprisoned for very long periods of time (for 10 to 30 years) for having consensual, completely safe sex, where they simply have not disclosed their status. Rock Hudson's lover, Marc Christian, successfully sued for $5.5 million because he was not told Rock Hudson had HIV – an inconceivable result here. (Marc Christian was not infected with the virus.) The HIV & AIDS Legal Clinic (Ontario) routinely receives calls from people with HIV/AIDS who think they can sue for invasions of their personal privacy, or for discrimination, when in fact the law – in Ontario at least – does not allow for such suits. So readers should be wary of being mislead.

On a positive note, it is clear that at least one of the authors of *The Rights of People Who Are HIV Positive* has extensive experience representing the interests of people with HIV/AIDS in courts and tribunals in the US. For a number of years Ruth Eisenberg was the legal director of the Whitman-Walker Clinic in Washington, a legal clinic that represents people with HIV/AIDS. William Rubenstein was a staff lawyer with the ACLU AIDS Project, and he and Lawrence Gostin are now law professors at prestigious law schools in the US. This experience of

Continued from previous page.

representing people with HIV/AIDS comes across very clearly, particularly at the end of each chapter, where the authors critique the existing law and make suggestions for change. The criticisms are from an HIV/AIDS-community perspective and for the most part are right on in their recommendations. The only notable failing in this regard is in the section concerning access to public health insurance. The vast majority of Americans access primary health care by paying for it through private insurance carriers or through group insurance plans offered by employers, but millions of Americans have no coverage at all and millions more have significant gaps in coverage. Despite the nightmare this causes for those living with HIV/AIDS in the US, the authors do not recommend state-provided universal medical care. Rather, they recommend that insurance companies be forced to change their plans so that they are less discriminatory, more portable, and more comprehensive. It appears that the American romance with privately provided health-care services is too monolithic for the authors to challenge.

Despite the fact that the law is constantly changing, *The Rights of People Who Are HIV Positive* is a useful, readable, and informative primer on the legal issues of importance facing people with HIV/AIDS. I only wish it were Canadian.

– reviewed by Ruth Carey

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[1] WB Rubenstein, R Eisenberg, LO Gostin. *The Rights of People Who Are HIV Positive*. Southern Illinois University Press, 1999.

AIDS Alibis: Sex, Drugs and Crime in the Americas[1]

***AIDS Alibis*, by self-described ethnographer-activist-writer Stephanie Kane, explores the meanings embedded in personal, cultural, and "expert" stories told about HIV/AIDS.**

Kane analyzes "the impact of contrasting discourse of public health and law as they affect and are affected by ordinary people's behavior and ideas, [and]... think[s] through the implications of these dynamic cultural associations in terms of viral transmission: how the genetic templates and psychic shadows of HIV may be moving and transforming in bodies, communities, and transnational networks."(p 8) The symbolism revealed in these stories "provide[s] keys to the political unconscious," of how "different people and cultures ... are struggling to come to terms with event of global proportions."(p 10)

The first two parts of the book, titled "Work" and "Escape," draw upon Kane's work in Belize and Chicago as an ethnographer contributing to public health HIV prevention efforts. In "Work," Kane contrasts the "cement ghettos of North America with the tropical periphery of Central America, characterizing the ways in which political and economic inequalities structure the nature and extent of individual risk."(p 13) In addition to considering the relationship between HIV and sex work in these two settings, stories from Belize illustrate how racism, fear, poverty, homophobia and myth shape understandings of AIDS: only white homosexual men get AIDS, or AIDS arose from American women having sex with dogs or Africans having sex with monkeys.

Kane criticizes the "expert public health explanation" that the gap between knowledge about HIV and risk behaviour arises from individual irrationality or incompetence or inadequate education strategies: "they usually ignore the impact of how bad law and policy can put entire populations at risk." (p 11) Recounting her experience working in public health trying to raise awareness and to effect institutional change to help prevent HIV transmission, she illustrates how official responses can backfire when failing to honestly acknowledge the cultural, social and structural context that HIV occupies. She offers the example of the British military's response to being advised of unsafe sex between their soldiers stationed in Belize and local prostitutes: rather than assume responsibility for promoting risk-reduction strategies directed to Belizean women and their own troops, officials forced closure of the local establishment, likely shifting soldiers away from a commonly known establishment where condom use could be mandated toward the higher-risk, unprotected activities initiated in unregulated bars.

Kane also criticizes government hypocrisy in the US: "Despite all the millions that the US government has spent on prevention education, it seems unlikely that it is serious about ending the pandemic. Indeed, prevention programs often seem like alibis set up to make it appear that representatives of the people care about their health and well-being. But if they really do care, then they would not perpetuate the biggest alibi in the Americas today: the US war on drugs ... Rather than protecting citizens, the drug war has recoded addiction, turning a social and medical problem into criminal justice business.... The US government has a drug war habit and a half-hearted public health agenda is its alibi, a claim to good intentions." (pp 3-4, 193-194)

The second part of the text acknowledges the need for "Escape" and the reality that "for most of us, there is no escape."(p 15). A funeral in Belize indicates the need for community ritual to come to terms with death. Narratives from the experience of Chicago men and women dealing with drug addiction reveal the damage of the drug war in its effects on patterns of social organization and HIV risk: "Keeping injection equipment illegal directly increased the probability that people would reuse needles and hence that HIV would circulate among shooters and their sexual partners.... The criminalization of addiction physically separates drug users by incarcerating them; our jails and prisons are overflowing with them. In the free world, criminalization ... tend[s] to hamper communication and increase HIV risk in the most intimate relationships." (pp 117-118)

In exploring "Work" and "Escape," Kane speaks as ethnographer, interpreting knowledge gained through dialogue and observation located in specific cultural locales. In turning to the theme of "Crime," Kane moves into the realm of cultural studies, analyzing narratives about criminalizing intentional HIV transmission, as constituted through court proceedings and news and entertainment media. "By presenting this topic for popular consumption and legal debate, the media oversee a phantasmagoric transformation of HIV from parasite to weapon. The modulation of HIV as an imaginative figure involves a shift in the focus of attention. As the primary subjects of AIDS intervention in the public health mode, the uninfected move into the background. In step the subjects of legal intervention, the already HIV-infected. More particularly, the focus is on HIV-positive persons who are said to have knowingly and willingly infected others." (p 16)

Drawing upon notorious US and Canadian criminal prosecutions for HIV transmission or exposure, Kane seeks "insight into the ways in which citizens in democratic states seek out the force of law to control fearful aspects of social change"(p 16) and the role of both law and media in "coding deviant bodies and sexual subjects."(p 17) Noting that states will continue to pursue prosecutions against individuals who risk transmitting HIV, Kane urges that criminal law be used only as a last resort: "The establishment of adequate treatment programs and social welfare supports for HIV-positive persons and a coherent and enforceable set of antidiscrimination laws should precede any further moves toward criminalization."(p 187) She also cautions that the impact of the "bad acts of a few individuals ... (and the impact that the interventions of criminal law might have on the interventions of public health more generally) must be weighed against potential damage caused by institutional practices." (p 18)

Delving into the "political unconscious of AIDS," Kane's work ultimately serves to remind us that "if institutions change the conditions under which *populations* engage in HIV risk behaviors, the fatal consequences of *individual* choice in global HIV transmission patterns will diminish markedly." (p 19).

– reviewed by Richard Elliott

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[1] S Kane. *AIDS Alibis: Sex, Drugs and Crime in the Americas*. Philadelphia: Temple University Press, 1998 (222 pp, ISBN 1-56639-628-X). Stephanie Kane is Assistant Professor of Criminal Justice, Indiana University; Adjunct Professor of Anthropology, Folklore Institute.

Les préjugés plus forts que la mort: Le sida au Québec[1]

In the late 1990s, although AIDS is on Québec's social agenda, it competes with several other issues to establish its own place in terms of government priorities and media interest. In *Les préjugés plus forts que la mort: Le sida au Québec* (Prejudices Stronger Than Death: AIDS in Québec), Carole Graveline, Jean Robert, and Réjean Thomas look at the history of reactions to the disease in the context of the social trends of the 1970s, 80s, and 90s.

From the outset, the authors adopt an unpretentious style, personal and reader-friendly. By way of prologue they provide a short history of themselves that immediately evokes an openness of mind and sense of empathy that will be the cornerstone of their approach throughout the rest of the book.

A brief description of the authors' involvement illustrates their common aspirations and convictions, and at the same time defines the orientation and objective of their book. Carole Graveline, a Radio-Canada journalist, is interested in health and social issues. News of AIDS entered her life for the first time in 1981, directly from the United Press International wire service. Jean Robert, a physician, suddenly became a patient too when he contracted tuberculosis at the beginning of his career. His becoming aware of the needs one has as a patient, combined with an interest in pneumology and STDs, led him to see AIDS "from the inside." Réjean Thomas was at the time hanging out in trendy places where he enjoyed the nightlife. Conscious of a clear lack of responsiveness and openness in the health-care system, he reacted to what he perceived as a need by starting up a clinic specializing in STDs.

In their capacity as witnesses in a privileged position to experience the emergence and development of HIV/AIDS in Québec, the authors throw a profoundly human light on the social aspects of a disease that cannot be cured by drugs. Through their personal experiences, they recount tales of desperate, stigmatized, outraged patients – people who felt above all else the need to be listened to and treated by professionals who wouldn't judge them.

The authors deal not only with the needs and emotions of the individual (as patient or caregiver in the context of HIV/AIDS), but also with all the social accomplishments of such individuals together with their community. The story, substantially annotated, begins with the creation of the Comité SIDA–Québec in 1982, to which event subsequent political, community, institutional, and individual positions are linked chronologically.

The authors' considerable experiences enable them to provide a rich and exhaustive description of many issues raised by HIV/AIDS, mainly as they arose during the 1980s, but still topical. They draw a portrait that is both comprehensive and detailed of various groups in society interacting with some aspect of AIDS: the values and reactions of the gay community, perceptions of homosexuality, other groups affected, etc. The authors deal with other issues associated with the expansion of research at the end of the 1980s: the link between disease and power, the question of confidentiality, opposing views in the public health field, the practice of clinical trials, etc. The book then discusses what occurred beginning around 1986, when the state system began to take control of these issues. The authors became indignant about this; in their words, "what you see now is structure. But how can a structure take into account people's needs? A structure solves problems. There is a huge difference between responding to a need and solving problems." (at 51)

Needs and the human aspect of the disease are at the heart of what Graveline, Robert, and Thomas are trying to highlight. The last part of their essay tells how they have fought to continually remind the system that AIDS is a disease at the crossroads of life, death, and love; that it is different from cancer, for example, because it involves prejudices, taboos, social judgments. They write of human rights infringed, case law that makes no real headway. They underline the emergence of new affected groups: women, Aboriginal people, the homeless. They denounce the "bureaucratic and political game" (at 69) for which a number of organizations have sold their soul in order to take part in the system and its "structure," whence the increasing popularity of words like "networking," "partnership," "interface," "multifaceted problem." (at 71)

In short, Carole Graveline, Jean Robert, and Réjean Thomas rebuke – in less than a hundred pages and without mincing words – the attitude adopted by the majority of Québec society for the last 15 years. They deplore the fact that a race for money and power has created an "AIDS industry" whose product is supposed to be the "solution" to "problems." Because, behind these structures, there are still very real, crying needs. Syringe exchange programs and methadone maintenance are not enough. The training of health professionals and teachers is inadequate for the care and prevention of HIV/AIDS. The interest and involvement of the media are only partial and are not sustained. Behind the ostensible problem, human beings continue to suffer and die.

– reviewed by Josée Dussault

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[1] Montréal: VLB Éditeur, 1998 (91 pages).

UPCOMING EVENTS

July 2000 Durban Conference to Address Rights Issues

Participants attending the XIIIth International AIDS Conference (AIDS 2000), to be held in Durban, South Africa (9-14 July 2000) will discuss legal, ethical, and human rights issues at two new forums, signifying the increased international focus on these issues for national and international responses to the HIV/AIDS epidemic.

Putting Third First – Critical Legal Issues and HIV/AIDS

On Friday, 7 July 2000 (just prior to AIDS 2000), the Canadian HIV/AIDS Legal Network and the AIDS Law Project, South Africa will host a one-day meeting on legal, ethical, and human rights issues. The forum, entitled *Putting Third First – Critical Legal Issues and HIV/AIDS*, will give participants from both developing and developed countries the chance to discuss a limited number of concrete issues in substantial depth. This opportunity does not usually occur at international AIDS conferences with abstract-driven sessions based on short presentations on many different topics. The meeting will also be open to people not attending AIDS 2000, and is timed to allow for participation in the Community Forum and other pre-Conference events scheduled for Saturday, 8 July.

Issues to be addressed will include access to treatment; criminal law and HIV/AIDS; legal and ethical issues relating to vaccines; and vulnerability of women and the role of the law. As the meeting's title (*Putting Third First*) suggests, the focus will be on legal strategies to advance the human rights of those most vulnerable to HIV/AIDS and to discrimination: people in the developing world and people who, although they live in the developed world, suffer from poverty and marginalization and are at high risk of contracting HIV. Four papers will be presented in plenary, with time for questions and discussion after each of the papers. The remainder of the day will be taken up with workshops at which key issues can be explored further.

The papers will be available at the meeting, and edited versions will be placed on the Network website and published in a special joint issue of the AIDS Law Project Newsletter and the *Canadian HIV/AIDS Policy & Law Newsletter*. Major sponsors of the meeting thus far include the United Nations Programme on HIV/AIDS (UNAIDS), the Government of Canada under the Canadian Strategy on HIV/AIDS, and the United States Agency for International Development (USAID). Other funders include the Office of AIDS Research, National Institutes of Health (NIH) and the Futures Group International. Additional funding is being sought.

For more information and registration, Canadians should visit the Legal Network's website at www.aidslaw.ca or contact Glen Bugg at gbugg@aidslaw.ca (tel: 514 397-6828 ext 226; fax: 514 397-8570). People from outside Canada should contact Fatima Rahiman, AIDS Law Project, Centre for Applied Legal Studies, University of Witwatersrand, PO WITS 2050, Johannesburg, South Africa (tel: 27 11 403 6918; fax: 27 11 403 2341; email: 125fa2ra@solon.law.wits.ac.za; website: <www.hri.ca/partners/alp/>.

Registration is limited to 100 participants on a first-come, first-served basis, and is US$50 (this fee can be waived, on request, for people with HIV/AIDS and for participants from developing countries).

New Conference Track on Rights, Politics, Commitment, and Action

Beginning on Sunday, 9 July 2000, participants at AIDS 2000 will continue the discussion of legal and policy issues through "Track E: Rights, Politics, Commitment and Action." Track E will give political and human rights issues a new level of prominence in the Conference scientific program.

For more information, visit the Conference website at <www.aids2000.com>.