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NEWSLETTER

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Injection Drug Use and HIV/AIDS: Another Call for Action

Two major reports released in 1997 concluded that the legal status of drugs in Canada contributes to the difficulty of addressing HIV among injection drug users. As a follow-up to these reports, and in light of their recommendations, Health Canada funded the Canadian HIV/AIDS Legal Network to further examine the legal and ethical issues surrounding HIV/AIDS and injection drug use. After 18 months of work and extensive consultations, a report with 66 recommendations,[1] a volume of background materials,[2] and as series of info sheets have now been released. The report points out that Canada's response to the public health crisis concerning HIV/AIDS and injection drug use is far from being concerted and effective, and calls once again for immediate action to prevent the further spread of HIV among injection drug users, and to provide better care, treatment, and support to those already affected.

The Urgency of the Situation

Canada is in the midst of a public health crisis concerning HIV/AIDS and injection drug use. The spread of HIV (and other infections such as hepatitis C) among injection drug users merits serious and immediate attention. The number of HIV infections and AIDS cases attributable to injection drug use

cont'd on page 13

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

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Health Canada Santé Canada

Newly Infected People & Clinical Trials: Ethical Issues

Traditionally, participants in clinical trials were usually in an advanced state of disease and facing early death. They were mostly well-educated, middle-class, gay white men. For many, the initial devastating shock of the diagnosis was far behind them. They had had time to deal with this shock and had gone through the difficult and often long process of disclosure to family and friends. The time between diagnosis and the decision to start therapy or to participate in a clinical trial had often given them the opportunity to become familiar with the various non-medical organizations where they could meet others going through similar difficulties. Many of them did not rely solely on physicians to make decisions. The attitude of many physicians was also different then, when little was known and little could be done to control viral replication. Physicians had abandoned their traditional role of healer and were acting more as sources of information and comfort. Until recently, treatment decisions were simpler because treatment options were limited and issues of cross-resistance and drug interactions were unknown.

cont'd on page 19

CONTENTS

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Comments?

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

CANADIAN HIV/AIDS POLICY & LAW NEWSLETTER

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

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

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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>.

EDITORIAL

Enough Is Enough

At the same time as we release this issue of the *Newsletter*, the Canadian HIV/AIDS Legal Network also releases a report with 66 recommendations, a volume of background materials, and a series of info sheets on legal and ethical issues related to injection drug use and HIV/AIDS. You will find an edited version of the executive summary of the report reproduced in this issue. Yet another report on injection drug use and HIV/AIDS? Did not the Task Force on HIV, AIDS and Injection Drug Uses release a national action plan in 1997, calling for immediate action at all levels of governmental and community leadership? And did that plan not rely, at least in part, on the recommendations developed at the "Second National Workshop on HIV, Alcohol, and Other Drug Use" held in Edmonton in February 1994? What happened to those reports, plans, recommendations, and calls for action? Far from enough. The inaction is striking, particularly if one considers that those responsible for it – and particularly the federal, provincial, and territorial governments, and public health authorities across Canada – should know better and should have learned their lessons from the Commission of Inquiry on the Blood System in Canada (the Krever Inquiry). But the lessons from that Inquiry – many directly applicable to the HIV/AIDS epidemic among injection drug users, as Skirrow

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so eloquently demonstrated in the last issue of the *Newsletter* – seem to be forgotten, or are applied whenever convenient, and otherwise neglected. Thousands of injection drug users have been infected with HIV and hepatitis C virus in the last years, many as a direct result of inaction. Their infections were preventable. And many more will become infected in the years to come unless immediate action is taken. To those who say that adopting the recommendations made in the many reports on the subject – or, indeed, any change in drug policy – would mean condoning drug use, I say that they are wrong, and that continuing what has not worked means condoning the preventable infection and death of thousands.

The inaction is striking, particularly if one considers that those responsible for it should know better and should have learned their lessons from the Commission of Inquiry on the Blood System in Canada.

Will the Network's report, volume of background materials, and series of info sheets make a difference? We show, once again, that the legal status of drugs in Canada contributes to the difficulties encountered in addressing HIV among injection drug users. However, we also show that much can be done now, without waiting for the much-needed legal changes, within the current legal framework. And we point out that much *must* be done because current approaches do not withstand ethical scrutiny:

> It is *ethically* wrong to continue criminalizing approaches to the control of drug use when these strategies: fail to achieve the goals for which they were designed; create evils equal to or greater than those they purport to prevent; intensify the marginalization of vulnerable people; and stimulate the rise to power of socially destructive and violent empires.

Enough inaction is enough.

Other articles in this issue of the *Newsletter* deal with topics as varied as AIDS vaccines, post-exposure prophylaxis, and discrimination in Canada's South Asian communities. Innovative initiatives are presented, such as the "Montréal Model" for responding to HIV-positive people who, without disclosing their serostatus, have sexual relations or use injection drugs without taking precautions to avoid HIV transmission. And updates are provided in areas in which our coverage has traditionally been strong: prisons and criminal law. Common to all articles is that they show that interventions that protect the rights of those living with, or affected by, HIV and AIDS are also those that will facilitate, rather than hinder, HIV prevention efforts and efforts to provide care, treatment, and support to those infected. For example, the fact sheet on vaccines that we reproduce demonstrates that there is no conflict between respect for human rights and the speedy development of a vaccine. And the article on the "Montréal Model" also shows that, while coercive interventions may become necessary, they can only be a measure of last resort. The link between health and human rights, so often the subject of articles in the *Newsletter*, is unfortunately still little understood. It will be explored further in the next issue of the *Newsletter*.

PREGNANCY AND HIV/AIDS

An Ethical Analysis of HIV Testing of Pregnant Women and Their Newborns

In the last issue of the *Newsletter*, we reprinted the executive summary of a paper providing the most compelling analysis yet of the medical and legal issues that should inform the policy debate regarding the HIV testing of pregnant women.[1] The following paper provides an ethical analysis of HIV testing of pregnant women and their newborns. It concludes that mandatory testing programs may be simpler and cheaper and, moreover, are directed at those who are most deserving – completely vulnerable, completely innocent newborns. Therefore, implementing mandatory testing could be pragmatically and politically tempting. Taking that course would, however, flout the respect for autonomy that a civilized society owes all its members; ignore the special consideration that a caring society owes its most vulnerable members; and violate the equal concern and respect that a just society owes its least fortunate members.

Introduction

Rapid developments in the diagnosis and treatment of HIV/AIDS highlight two crucial features of practical ethics: the importance of moral considerations in policy analysis and development, and the need to remain open-minded and flexible when making moral assessments. The promising results of clinical trials and the quest to develop a vaccine continually spawn new hope, and hope, in turn, breeds therapeutic enthusiasm. But as Carol Levine and Ronald Bayer, two early analysts of the ethics of HIV/AIDS, recognized a decade ago, therapeutic enthusiasm can suspend moral scrutiny:

> It is precisely when medicine's capacity to enhance patient welfare appears to be increasing that there is a danger that important ethical concerns can be overridden or disregarded. This is especially so in the case of AIDS – a disease that will continue to exact an enormous toll in human suffering for the foreseeable future and that continues to have a social and cultural impact far beyond the numbers of people affected.[2]

Moral vigilance is most needed when expanding medical capacities offer the prospects of reducing pain and suffering and extending life. At such junctures a moral appraisal can prompt a second look at the evidence for anticipated benefits and risks to health and life; can identify a broader range of benefits and risks that could be relevant to people with HIV/AIDS; and, by recognizing the unavoidable uncertainty in decisions about what to do, can ask who should have the authority to make those decisions.

Moral principles and values must be reinterpreted and reassessed as clinical circumstances change. Their applications must appreciate the situations in which people with HIV/AIDS live and must be sensitive to the broader contexts within which policies will operate. Levine and Bayer also foresaw that the social and political consensus about specific, informed consent to testing and the confidentiality of test results that was forged a decade ago, in a context of "relative therapeutic impotence," would be challenged as new clinical options emerged.[3] The warning they issued then still needs to be heeded:

> The next phase of the HIV epidemic will ... be marked by improvements in therapies and by profound challenges to the ethical principles that should govern the practice of medicine and public health. Only if careful consideration is given to the rights of individuals, to respect for their privacy, and to society's obligations to provide the needed clinical and social services will it be possible to assure that the cautious optimism that is now medically justified will be translated into policies that are ethically justified.[4]

With their warning in mind, we can consider what approach to the testing of pregnant women and their newborns would be ethically justified now.

The Current Clinical Context

Perinatal (or vertical) transmission of HIV infection from mother to child can occur either in utero (in the mother's uterus), during delivery, or after birth, apparently by way of breast milk. In the absence of intervention, the rate of perinatal transmission varies from 15 percent to 25 percent.[5]

Until 1994, knowing the serostatus of either mothers or infants was of limited therapeutic value. In 1994 preliminary results from Pediatric AIDS Clinical Trials Group protocol 076 (PACTG 076) showed a reduction in perinatal transmission from an estimated rate of 25.5 percent among untreated women to 8.3 percent among women in the treatment group.[6] PACTG 076 involved a regime of the antiretroviral drug zidovudine (ZDV, also known as AZT), which rapidly became recognized as the standard of care for HIV-positive pregnant women and their newborns. Final results from PACTG 076, reported in 1996, closely matched the initial findings,[7] and even more dramatic reductions in perinatal HIV transmission have since been reported in British Columbia and Québec.[8] Subsequent research has demonstrated the superior effectiveness of combination therapy, involving two or three antiretroviral agents rather than ZDV alone. This is now the recognized standard of care for pregnant HIV-positive women and their newborns.[9]

> The principal moral argument for voluntary testing is that it respects a woman's autonomy.

The availability of a demonstrably effective regime for reducing perinatal transmission of HIV changed the ethical debate about HIV testing. Even after pregnancy is recognized, something can now be done to reduce the chances that an HIV-positive infant will be born to an HIV-positive mother. The prenatal regime is not without risks for mother and child,[10] however, and "the long-term consequences for the infant who has been exposed to antiretroviral drugs in utero are unknown."[11] Further complicating the issue is the lack of effective and comprehensive mechanisms in Canada and the United States for collecting information about the risks of using antiretroviral drugs during pregnancy.[12]

Although the case for testing is bolstered by the therapeutic benefits that testing now makes possible, the strength of that case also depends upon the nature of the information that testing provides. If administered properly, the tests available for detecting HIV infection in adults, including pregnant women, are extremely sensitive and specific. By comparison, testing newborns for HIV infection remains highly imperfect. Roughly three-quarters of the newborns who test positive using the conventional serologic techniques for testing adults are not actually infected, but are carrying their mothers' antibodies, and there is no way to distinguish the two groups at the time of initial testing. Those infants "who are not truly infected usually lose their maternal antibodies by 15 to 18 months of age, after which time they test negative for the HIV antibody."[13] Positive results of tests on newborns do, however, indicate the serostatus of their mothers; thus any proposal for mandatory testing of newborns is also a proposal for mandatory testing of their mothers.

Tests using polymerase chain reaction (PCR) to detect the presence of HIV DNA in blood samples are less likely to generate false positive results, but they also generate a high percentage of false negatives, at least immediately after birth. Using such tests, "HIV infection can be definitively diagnosed in most infected infants by age 1 month and in virtually all infected infants by age 6 months."[14] But these tests will identify fewer than half of the truly infected infants within 48 hours after birth, and it is within this short period of time that the current standard of care specifies that antiretroviral prophylaxis should begin if it is to be as effective as possible.[15]

Testing of Pregnant Women

The principal moral argument for voluntary testing is that it respects a woman's autonomy. A meaningful exercise of individual liberty requires that a woman's decision be informed and voluntary. Consequently, pre-test counseling is required, and a decision must not be unduly pressured or compelled, either by persons or by circumstances. Such an exercise of autonomy is good in itself, or intrinsically good, because it allows the woman to make an important decision about her life in terms of her own values and beliefs. That she is the one who decides – that it is her decision – has value in itself.

Moreover, recognizing the uncertainty inherent in a testing decision strengthens the woman's entitlement to make it. While the evidence for the short-term benefits of treatment to a woman and to her fetus or newborn is strong, the long-term risks of that treatment for a mother and her infant are unknown. In any clinical undertaking, whether treatment or research, the first question that has to be asked, medically and morally, is whether the prospective benefits outweigh the potential harms. Determining whether the benefit-to-harm ratio is favourable requires not merely that the benefits and harms be identified and their probabilities be estimated but also that they be appraised and compared. Such an evaluation requires values, but what values? And whose values?

Respect for autonomy entails that the values of the woman structure the comparison of benefits and harms and govern the conclusion about whether the benefit-to-harm ratio is acceptable. She should make the decision about testing for two reasons: she knows her own values better than anyone else, and furthermore she might utilize a broader range of values than would be included in a narrower clinical or public health perspective.

Allowing the woman to decide also is more likely to produce beneficial outcomes and in that respect is instrumentally good as well. Respecting her autonomy, and thereby respecting her as a person, is a way of establishing or preserving her trust in the physician–patient relationship and in the health-care system. Trust is important because there are practical, as well as moral, limits to how far compulsion can reach. A woman ultimately controls what happens to her and her fetus and, unless the drastic step of removing her child from her custody is taken, her newborn as well. If testing is compulsory, she might not return for the result of her test; she might refuse an offer of treatment; or she might not adhere to a therapeutic regimen that is widely recognized as demanding.[16] Testing is only a means to treatment, and successful treatment requires consent and cooperation. The sense that she is being respected as a person, the realization that she is responsible for what happens to her and to her fetus or newborn, and the conviction that the information she is receiving is accurate and that the advice and recommendations she is being given are in the best interest of herself and her fetus or newborn are essential to eliciting that cooperation.

The success of any testing program must ultimately be determined not by how many tests have been performed, but by whether the benefits that provide a rationale for testing in the first place have been realized. Achieving that goal needs the cooperation of the women who are tested, and treating them as ends in themselves and not merely as means encourages that cooperation.

The success of any testing program must ultimately be determined not by how many tests have been performed, but by whether the benefits that provide a rationale for testing in the first place have been realized.

In addition, voluntary HIV testing retains a moral parity with other forms of prenatal testing. Pregnant women are not required to undergo prenatal testing for genetic diseases that can cause enormous pain and suffering, seriously impair physical and mental functioning, and shorten lives. Unless distinctive, morally relevant features of HIV infection can be identified, forcing pregnant women to be tested for it but not for other comparable diseases that might be transmitted to their newborns would be discriminatory.

Testing of Newborns

A decade ago, Levine and Bayer concluded:

> Only when a definitive test that accurately identifies HIV-infected infants becomes available, and when a treatment has been demonstrated to be safe and effective in prolonging life and improving its quality for the child, will overriding parental refusal for HIV testing be ethically defensible.[17]

Whether this position should now provide a moral warrant for manda-

tory testing requires two new judgments.

One is whether the clinical conditions have been satisfied. Recent guidelines on the use of antiretroviral therapy for pediatric HIV infection offer the following answer:

> Early identification of HIV-infected women is crucial for the health of such women and for care of HIV-exposed and HIV-infected children. Knowledge of maternal HIV infection during the antenatal period enables a) HIV-infected women to receive appropriate antiretroviral therapy and prophylaxis against opportunistic infections for their own health; b) provision of antiretroviral chemoprophylaxis with ZDV during pregnancy, during labor, and to newborns to reduce the risk for HIV transmission from mother to child; c) counseling of infected women about the risks for HIV transmission through breast milk and advising against breastfeeding in the United States and other countries where safe alternatives to breast milk are available; d) initiation of prophylaxis against Pneumocystis carinii pneumonia (PCP) in all HIV-exposed infants beginning at age 4-6 weeks in accordance with [United States Public Health Service] guidelines; and e) early diagnostic evaluation of HIV-exposed infants to permit early initiation of aggressive antiretroviral therapy in infected infants.[18]

Thus, the health benefits that attend testing are now potentially substantial.

What is morally fundamental, though, is the second judgment, which involves a comparison of a broader array of potential benefits and harms. In particular, how are the harms to a child that might result from its mother's refusal of testing to be compared with the harms that might be inflicted on a mother by mandatory testing of her newborn?

It is tempting to argue for mandatory testing by stressing the potential benefits for newborns and the complete vulnerability of newborns. Yet there are competing vulnerabilities here. Many women whose newborns might be tested are likely to be poor, stigmatized, and discriminated against for a variety of reasons, and these features can hide rather than expose their vulnerabilities. The moral danger is that concern for them can easily be subordinated to concern for their "innocent" fetuses or newborns. Policy initiatives could treat these women "as mere vessels or vectors of disease."[19] Women, in other words, could become means to the attainment of ends that are regarded as self-evidently desirable for their infants.

Specific arguments for mandatory testing of newborns combine an empirical claim and a moral claim. The empirical claim is that voluntary testing programs do not work, and we return to this claim later.

The moral claim is that the potential benefits of treatment are so great that they outweigh the wrongs that mandatory testing would do to women by not respecting their autonomy and the harms that mandatory testing would impose on women by exposing them to stigmatization and discrimination. For women who are infected, testing not only gives them the prospect of treatment but also provides them with knowledge that could be used to decrease the risk of transmission and to make better-informed decisions about their lives and the lives of their loved ones. For newborns who are infected, the benefits are seen as even more morally compelling because treatment can substantially improve their quality of life and extend their lives. The moral case for mandatory testing of newborns, in other words, posits a conflict between the rights of women and the rights of newborns and then contends that the rights of newborns should prevail. But when the rights of a newborn are pitted against the rights of its mother, how is the case for the priority of the newborn's rights made?

Sometimes the argument emphasizes the helplessness and vulnerability of newborns. Even if women infected by or at risk of acquiring HIV are vulnerable in many ways, their infants are more vulnerable still:

> No member of society is more dependent and vulnerable than a newborn child. When an infant is born with HIV or any other potentially life-threatening disease, it is even more defenseless. A mother's duty is to protect her child by accepting health care for the child, as well as for herself. When a mother refuses HIV testing of her child, she is not fulfilling her parental responsibility. Extreme measures are needed to ensure that these infants get the fair chance they deserve.[20]

A mother's behaviour need not be careless, illicit, or promiscuous; the mere opportunity to avoid becoming infected is sufficient to subordinate her interests to the interests of her newborn, who of course had no such opportunity.

At other times, the ranking of values is quite abstract. The argument of

sociologist Amitai Etzioni is as general as the philosophical method he disavows:

> In ranking the rights and values involved, one may draw on abstract ethical theories, such as weighing autonomy against beneficence.... [I]nstead I draw mainly on the core values of the democratic society in which these issues must be worked out. As I see it, these values provide clear guidance.... Our core values and the legal code that expresses them generally rank the loss of life over that of limb, and both higher than the loss of property. Other concerns are less clearly ranked but usually do not take precedence over life, or knowingly allowing a major illness to fester when it can be treated.[21]

Etzioni recognizes that there are potential harms to both mother and infant and that those harms need to be compared: "The main issue ... is not whether autonomy is being infringed upon and to what extent, but whether another consideration justifies whatever diminution of autonomy is entailed."[22] Given Etzioni's abstract and decontextualized hierarchy of values, though, causing "irreparable harm to a defenseless infant" is more than enough to justify whatever infringement of autonomy is needed to avoid that harm.[23]

There are two problems with this defence of mandatory testing of newborns. First, the putative competition between maternal and fetal interests is skewed because other potential harms to mothers are minimized if not simply dismissed. Opponents of mandatory testing argue that it could, for instance, deter women from seeking prenatal care or treatment and undermine adherence to treatment and attempts to reduce the risks of transmission. Yet Etzioni rejects all such claims, along with counterclaims made by proponents of mandatory testing: "Observations by both sides ... are anecdotal; until systematic data are generated, it seems that this particular argument cannot be used any more to oppose ... [mandatory testing] than to support it."[24] Uncertainty does not entail irrelevance, however. Trust has a powerful effect on behaviour, and so does distrust. A mother's distrust could harm herself or her fetus or newborn, and those potential harms cannot simply be wiped from the moral slate.

Similarly, proponents of mandatory testing downplay worries about stigmatization and discrimination and reprove opponents of mandatory testing for continuing to live "in a culture of fear and suspicion more appropriate in the early years of the epidemic than today."[25] Neither the pervasiveness nor the virulence of stigmatization and discrimination has changed, though. In fact, the threat of discrimination has in some ways become more overt, as a person on combination therapy tellingly confirms: "I was able to remain invisible living with HIV until two years ago. Now I have to carry my bag of medications around all the time – I am always visible. I carry my stigma around."[26] And rather than easing, familiar forms of discrimination have simply become more subtle and covert:

> In the past ... people may have been fired outright when it was discovered that they were HIV-positive. Today they may be laid off for what are ostensibly other reasons or they may be harassed and pressured to the point that they quit their jobs or go on disability. Fear of being identified at work and of losing their job in fact prevents some people from taking HIV-related medications."[27]

The communities and societies within which people with HIV/AIDS live have not become so tolerant, so accepting, and so benign that the stings and the harms of stigmatization and discrimination can be belittled.

The communities and societies within which people with HIV/AIDS live have not become so tolerant, so accepting, and so benign that the stings and the harms of stigmatization and discrimination can be belittled.

Second, the plausibility of an alleged conflict between mothers and infants depends upon the way that conflict is carefully and abstractly framed. The presumption behind proposals for mandatory HIV testing is that women cannot be relied upon to act in ways that an external observer would define as being in the best interests of their children: interests that are seen as distinct from and

Mandatory testing should be considered only if there is conclusive evidence that well designed and adequately funded voluntary testing programs do not work. As of now, that evidence does not exist.

opposed to their own interests. More concretely, the apparent reluctance of pregnant women to be voluntarily tested is cited as evidence of indifference to the health and welfare of their children.[28]

That inference is premature. If the existence of a conflict between mothers and their children is accepted at all, that acceptance should come at the end not the beginning, and it should be a firm signal that morality and public policy have failed. Mandatory testing should be considered only if there is conclusive evidence that well designed and adequately funded voluntary testing programs do not work.

As of now, that evidence does not exist. Uptake rates for voluntary HIV testing programs are widely variable, ranging from 12 percent in Ontario to 80 percent in British Columbia.[29] The low figure from Ontario is apparently attributable to a provincial policy of offering testing only to women in defined high-risk groups, which has now been changed. In the United States, similar variability exists in the percentages of women who request voluntary testing, with at least one program reporting an uptake rate of 95 percent.[30] The reasons for these differences need to be understood, and addressed as matters of public policy, before any data about low uptake rates can be used to argue for mandatory testing.

The inference is also inappropriate because it ignores the realities of life for many women with HIV/AIDS. Because of their social and economic marginalization, these women confront substantial barriers to care. Keeping medical appointments, for example, is difficult when one must manage the demands of family members and cannot simply hop in a car. A woman could avoid testing because she fears violence or abandonment if her partner discovers she is infected, which would worsen an already bleak economic situation. Women who are poor and multiply vulnerable must constantly juggle the exigencies of daily life and may have to balance their own health-care needs against those of existing children as well as a fetus or newborn.[31] In such contexts, a woman's decision to forego testing is not necessarily reprehensible or irrational, given the demands that press upon her and the options available to her.

A morally enlightened approach to testing would not pit vulnerability against vulnerability. A morally inspired and sympathetic approach would, instead, presume that the interests of women and the interests of their children are congruent and would strive to promote all those interests.

When a conflict between mother and child is portrayed so starkly and abstractly, women cannot win. But a morally enlightened approach to testing would not pit vulnerability against vulnerability. A morally inspired and sympathetic approach would, instead, presume that the interests of women and the interests of their children are congruent and would strive to promote all those interests. It would assume that mothers care for their children and want to do what is best for them even if that requires personal sacrifice. It would seek to understand the barriers that deter women from courses of action that seem to be in their own and their children's best interest and require, as a matter of public policy, that those barriers be reduced or eliminated. Voluntary testing has the potential to do all that. Mandatory testing should be a last resort.

The governing moral principle for assessing testing policies should be that interventions aimed at protecting health must exhaust the range of measures that can be taken to do things for people before state power is used to begin doing things to people.

Final Remarks

In the present context, the governing moral principle for assessing testing policies should be that interventions aimed at protecting health must exhaust the range of measures that can be taken to do things for people before state power is used to begin doing things to people. There are two related threats to this principle. One is the contention that voluntary testing programs do not work – that too many pregnant women, their fetuses, and their newborns are being deprived of the potentially substantial benefits of new therapies because the uptake rates for voluntary testing are too low. The evidence for this contention is inconclusive. What needs to be demonstrated are that the uptake rates for well designed, implemented, and funded voluntary testing programs are too low, and that mandatory testing could do better. Neither claim is currently tenable.

The other threat emanates from the perceived burden that voluntary testing programs that have a good prospect of working – where the criteria for success include not simply the number of tests performed but also the realization of the benefits that testing makes possible – would impose on the health-care system. The resources that such programs might require could seem inordinate. That, too, is a claim that remains unsupported. Novel, creative ways of providing pre-test and post-test counseling need to be investigated, along with the availability and accessibility of newly emerging therapies.

What is morally worrisome about both threats is the hidden assumption that the efforts and the resources that might be needed to provide successful voluntary testing programs are not worth it. Mandatory testing programs are simpler and cheaper and, moreover, are directed at those who are most deserving – completely vulnerable, completely innocent newborns. That course could be pragmatically and politically tempting. Taking that course would, however, flout the respect for autonomy that a civilized society owes all its members; ignore the special consideration that a caring society owes its most vulnerable members; and violate the equal concern and respect that a just society owes its least fortunate members.

– Barry Hoffmaster & Ted Schrecker

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New Law on Testing of Newborns in Connecticut

A new law in Connecticut directs health-care providers to screen newborns for HIV if the mother was not tested during prenatal care.[1]

Beginning on 1 October 1999, health-care providers will be required to inform each woman receiving prenatal care that HIV testing is routine. She is to be counseled that testing may be of benefit to her and her offspring, and that the results are confidential under state law. The woman must provide informed consent before a test can be conducted.

If a test has not been documented in the woman's chart prior to delivery, the health-care provider who is to deliver the baby must advise her about the value of testing. In the absence of a specific objection, the test is to be conducted, either before delivery or within 24 hours of delivery. The statute further requires that every institution caring for newborn infants must conduct an HIV test as soon as medically appropriate, unless the mother has already had an HIV test.

The law also authorizes the state Department of Public Health to establish a registry of data on infants who have been exposed to HIV or AIDS medication. The registry is to be used to study the potential long-term effects of the medications on infants.

Connecticut now is the third state in the US to require HIV testing of infants. New York's law requires testing of all newborns. Indiana authorizes testing within 48 hours after birth if the attending physician believes that testing is medically necessary.

[1] Reported in *AIDS Policy & Law* 1999; 14(13): 7.

US: Court Denies Legal Custody of Child to Breast-feeding Mother with HIV

In April 1999 an Oregon court refused to return legal custody of a baby to his HIV-positive mother who indicated she would breast-feed the child.

The mother was diagnosed with HIV during prenatal screening. Shortly after the baby's birth, she began breast-feeding him in the hospital, and a physician notified child protection authorities, who subsequently obtained legal custody. In seeking to regain custody of the child, the parents reportedly argued that HIV does not cause AIDS and that HIV cannot be transmitted through breast-feeding. Medical experts called by the state testified to the contrary that breast-feeding carries a very high risk of transmission. The court ruled that: "The parents may choose to run that risk with the child, but the court may second-guess that decision." Although *legal* custody has not been returned to the mother, the four-month-old child is allowed to live with his parents, and a child protection caseworker will visit periodically, ostensibly to ensure that he is not being breast-fed.[1] Available newspaper reports made no comment on whether such visits can achieve this objective.

[1] Hearing set for HIV-positive mother who wants to breast feed. *Oregon Live NewsFlash Online,* 16 April 1999; Doctor: HIV mom playing Russian roulette with tot. *Salt Lake Tribune Online,* 20 April 1999; HIV-infected mother loses fight for baby. *Los Angeles Times*, 21 April 1999, A13; A Young. Baby not returned to HIV mother. *Associated Press*, 20 April 1999, <www.ap.org>.

Injection Drug Use and HIV/AIDS: Another Call for Action

cont'd from page 1

has been climbing steadily. By 1996, half the estimated new HIV infections were among injection drug users.

Drug-injection risk behaviours among injection drug users are prevalent. The sharing of needles is an efficient mode of transmission of HIV (and other infections) and is relatively common among injection drug users. Sharing of other injection drug equipment such as spoons/cookers, filters, and water – known as "indirect sharing" – is also associated with HIV transmission. A shift from heroin use to increasing use of cocaine may be a significant factor in the escalation of HIV prevalence and incidence. Cocaine users may inject as often as 20 times a day. Rates of injectable cocaine use are especially high in Vancouver, Toronto, and Montréal, but cocaine use is also an increasing problem in other cities, including Calgary, Winnipeg, and Halifax.

Sexual risk behaviours are also prevalent. Many injection drug users are involved in unprotected commercial sex, and condom use with regular and casual opposite-sex partners is low, as it is among a substantial minority of male injection drug users who have sex with men.

The dual problem of injection drug use and HIV infection is one that ultimately affects all Canadians. However, some populations are particularly affected: women, street youth, prisoners, and Aboriginal people.

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The Project

Two major reports released in 1997 concluded that the legal status of drugs in Canada contributes to the difficulty of addressing HIV among injection drug users.[3] As a follow-up to these reports, and in light of their recommendations, Health Canada funded the Canadian HIV/AIDS Legal Network to further examine the legal and ethical issues surrounding HIV/AIDS and injection drug use. In three national workshops held between November 1997 and March 1999, the Network brought together 50 individuals from across Canada with knowledge and experience in matters related to HIV/AIDS and injection drug use to

1. identify legal and ethical issues pertaining to
   (a) the care, treatment, and support of drug users with HIV/AIDS; and
   (b) measures to reduce the harms of drug use;
2. undertake an analysis of a number of priority issues identified by workshop participants; and
3. propose recommendations on the priority issues.

Issues Analyzed

Seven priority issues have been analyzed:

1. What is the impact of the current legal status of drugs and drug use on efforts to prevent HIV infection among injection drug users and on the provision of care, treatment, and support to drug users with HIV/AIDS? What are alternatives to the current legal regime on drugs and drug use? What legal and ethical issues are raised?
2. What legal and ethical issues arise in circumstances in which illegal drug use is permitted in the course of providing health care and social services – primary health care, community clinics, pharmacy services, residential care, palliative care, housing services – to drug users?
3. Is it legal and ethical to make cessation of drug use a condition for treatment of a drug user? Is it legal and ethical to withhold antiretroviral drugs from HIV-positive drug users?
4. What legal and ethical issues arise in the context of prescribing opiates and controlled stimulants to drug users in Canada?
5. What legal and ethical issues are raised by (a) the absence of clinical trials on the impact of illegal drugs on the immune system; (b) the absence of research on the interactions between HIV/AIDS drugs and illegal drugs; and

(c) the exclusion of drug users from clinical trials involving HIV/AIDS drugs?

6. What are the legal and ethical grounds for ensuring that health-care providers, drug users, and the general public have accurate and complete information on illegal drugs and their effects?
7. What legal and ethical considerations should be taken into account when implementing needle exchange and methadone maintenance programs directed at reducing the harms from drug use?

The Current Legal Status of Drugs

The first issue studied is the impact of the current legal status of drugs on injection drug users as well as on efforts to prevent HIV infection, and to provide care, treatment, and support to injection drug users.

The *Controlled Drugs and Substances Act* takes a punitive approach to individuals who consume illegal drugs. Persons who possess drugs listed in the Schedules to the Act can be imprisoned for several years. Injection drug users can also be prosecuted for trafficking, which includes not only selling, but also giving, administering, transporting, or delivering an illegal drug. They may also be incarcerated if they possess needles, syringes, or other drug equipment that contain traces of illegal substances.

The criminal approach to drug use has several effects on drug users, health-care professionals, and society at large, and may increase rather than decrease harms from drug use:

- Because drugs can only be purchased on the underground market, they are of unknown strength and composition, which may result in overdoses or other harms to the drug user.
- Fear of criminal penalties and the high price of drugs cause users to consume drugs in more efficient ways, such as by injection, that contribute to the transmission of HIV and hepatitis.
- Because sterile injection equipment is not always available, drug users may have to share needles and equipment, which further contributes to the spread of infections.
- Significant resources are spent on law enforcement, money that could instead be spent on prevention and the expansion of treatment facilities for drug users.

Alternatives to the current approach to drug use and drug users in Canada are possible.

The most pronounced effect, however, is to push drug users to the margins of society. This makes it difficult to reach them with educational messages that might improve their health and reduce the risk of further spread of disease; makes users afraid to go to health or social services; may make service providers shy away from providing essential education on safer use of drugs, for fear of being seen to condone use; and fosters anti-drug attitudes toward the user, directing action toward punishment of the "offender" rather than fostering understanding and assistance.

Alternatives to the current approach to drug use and drug users in Canada are possible. Alternatives within the current prohibitionist policy that would not require any changes to the current legal framework could include the de facto decriminalization of cannabis possession for personal use, medical prescription of heroin, explicit educational programs, etc. Alternatives to the current prohibitionist approach may require that Canada denounce several international drug-control conventions.

From an ethical perspective, considering alternatives to the current approach is not just possible, but required. Ethical reflection on the current situation involves recognizing those aspects of current drug policy that must be reversed because of their intolerable social consequences. Ethical principles demand a more coherent and integrated drug policy that can withstand rational inquiry and scrutiny, is responsive to the complexity of the current situation, and allows for public and critical discussion. Ethical reflection should lead to a recognition of what components of current drug policy need to be maintained, what components need to be reversed because of their intolerable social consequences, and what alternatives need to be explored and submitted to controlled experiments.

On the basis of these observations, two overarching directions for future action were identified:

1. Canada must reverse the negative impacts of the current legal status of drugs on drug users and on those who provide services to drug users; and
2. Canada must move to adopt alternatives to the current approach to reducing drug use, and the harms of drug use, among Canadians.

In the long term, the goal must be to institute a more constructive alternative to the current legal status of drugs. In the short term, within the current legal and policy framework,

implementing the recommendations in the Report would allow for better provision of care, treatment, and support to drug users, and for more effective efforts to prevent HIV infection and other harms associated with drug use.

Drug Use and Provision of Health and Social Services

The second issue studied is the use of illegal drugs by drug users in healthcare and social service facilities.

Tolerating drug use in the course of providing health care and social services departs from the principle of abstinence as the only acceptable premise, standard, or goal in providing services to drug users. The principle of abstinence is deeply ingrained in drug policies and programs in North America. It has been reconsidered, however, in Europe and other jurisdictions, where there have been a variety of social experiments, including tolerating "injecting rooms" where drug users can come together, obtain sterile injection equipment, condoms, advice, and medical attention. In Canada, the Task Force on HIV, AIDS and Injection Drug Use recommended that the continuum of available services be enhanced by providing treatment options that do not require total abstinence from all drugs.

From a legal perspective, healthcare professionals who tolerate or permit illegal drug use on the premises may be prosecuted under the *Controlled Drugs and Substances Act* or subjected to disciplinary action (such as fines or the loss of their professional licence). However, there are a number of ways that criminal prosecution or liability may be avoided. For example, a healthcare professional may claim that allowing the use of illegal drugs was a necessity for the treatment of the patient; may be able to arrange for access to a specific drug under existing legislation; or might obtain exemptions under section 56 or section 55 of the *Controlled Drugs and Substances Act*.

From an ethical perspective, the *basic issue* is the ethical imperative to mobilize and maintain services necessary to assist people. To adhere to the ethic of humanity, behaviour should not be imposed on drug-dependent individuals that exceeds their current levels of ability. *Derivative ethical issues* include: whether it is ethically justifiable to allow or tolerate illegal drug use in residences and within palliative care services; how a facility can permit illegal drug use without losing its licence or social authorization to operate; staff concerns about condoning or even collaborating in offences against the law; to what extent staff can allow a resident to continue to deteriorate under drug use; and what rules should be established and enforced regarding tolerable and intolerable behaviour.

Among other things, the Report recommends that, in the short term, guidelines for ethical practice be developed by professional associations that address the situations of service providers who may be caught between legal constraints and ethical imperatives in providing services to HIV-positive drug users. The Report also offers long-term recommendations, including decriminalizing possession of currently illegal drugs for personal use.

Treatment

The third issue studied is poor access to medical treatment by HIV-positive injection drug users. Is it legal and ethical to make cessation of drug use a condition for treatment of a drug user? Is it legal and ethical to withhold antiretroviral drugs from HIV-positive drug users?

It is unethical to insist on cessation of drug use as a condition of medical treatment if this is beyond the capabilities of the drug user. It is also unjust to judge people as likely to be noncompliant with antiretroviral therapy simply because they are drug users.

Antiretroviral therapy (ART) has led to significant improvements in the health and quality of life of many HIV-positive people, and has reduced morbidity and mortality. HIV-positive drug users, however, are not offered ART with the same frequency as other HIV-positive people.

From a legal perspective, withholding medical treatment from HIV-positive drug users or compelling abstinence as a condition of medical treatment may, in some circumstances, violate sections 7 and 15 of the *Canadian Charter of Rights and Freedoms.* Federal and human rights legislation also prohibit discrimination against persons with disabilities, which likely provides some protection for drug-dependent persons.

It is also unethical to insist on cessation of drug use as a condition of medical treatment if this is beyond the capabilities of the drug user. It is also unjust to judge people as likely to be noncompliant with ART simply because they are drug users, and to withhold ART on this basis. Adherence to treatment is pro-

foundly affected by systems of care. When the health-care system is adapted to meet the needs of socially marginalized and indigent persons, there is a vast improvement in adherence to treatment. Ethics therefore requires that we not reduce an assessment of treatment compliance to simply the personal characteristics of people with HIV/AIDS. At the same time, there may be situations where it may be justified to delay or, at the extreme, refuse ART. Such a decision would be ethically unjustifiable if it is reached without honouring the characteristics of an authentic healing relationship: humanity (respect for the full biological and biographical particularity of the person with HIV/AIDS); autonomy (respect for the person's way of life and life plans); lucidity (transparent sharing of all relevant information); and fidelity (understanding and respect for the expectations of the sick).

The Report therefore recommends that:

- as a matter of principle, treatment should not be refused or withheld simply because someone is a drug user;
- the governing approach in providing care and treatment to HIV-positive drug users should be to adapt the therapeutic regimen to the needs of the individual, rather than require the individual to adapt to a preconceived clinical ideal;
- a network of physicians with experience in providing care and treatment to drug users be developed;
- simpler HIV drug regimens be developed to make adherence easier; and
- support be provided to drug users who require assistance in adhering to their regimen of HIV therapies, including outreach programs to deliver HIV therapies to drug users.

Prescription of Opiates and Controlled Stimulants

The fourth issue studied is the prescription of opiates and controlled stimulants to drug users. The *Controlled Drugs and Substances Act* and the Narcotic Control Regulations strictly delineate the circumstances in which a physician can prescribe a narcotic. Physicians and other health-care professionals who violate these laws and regulations may be subject to criminal prosecution.

Scientists in Canada would like to conduct a study of heroin for the treatment of drug-dependent persons.

Currently, methadone is the only opioid approved for the long-term treatment of drug-dependent persons in Canada. Although methadone maintenance has many advantages, it is not appropriate treatment for all drug-dependent persons. In contrast to such countries as Switzerland, Britain, Australia, and the Netherlands, Canada has been reluctant to allow medical professionals to prescribe other drugs to treat drug users. Scientists in Canada would like to conduct a study of heroin for the treatment of drug-dependent persons. Health Canada approval is required in order to conduct such a trial. Canada's status as a signatory to international drug-control treaties does not present an insurmountable barrier to the prescription of controlled substances.

From an ethical perspective, those who oppose methodologically sound clinical trials of opiate-assisted treatment programs are promoting the "therapeutic abandonment" of those who cannot benefit from existing treatments. The Report therefore recommends that, in the short term, pilot projects in prescribing heroin, cocaine, and amphetamine be initiated in Canada. In the long term, plans should be developed for the prescription of opiates and controlled stimulants and for the decriminalization of currently illegal drugs.

Drug Users and Studies of HIV/AIDS and Illegal drugs

The fifth issue studied is the lack of adequate clinical information upon which to base treatment of HIV-positive drug users. Drug users are excluded from studies of HIV/AIDS drugs. In addition, there is little research into the effects of currently illegal drugs on the immune system, or the interaction between HIV/AIDS drugs and currently illegal drugs. This hinders the provision of optimal care, treatment, and support to HIV-positive injection drug users. HIV-positive drug users may have a wider range of immunological deficiencies and a different history of the disease; they may respond differently to treatments than other HIV-positive persons.

It is ethically wrong to exclude drug users from the clinical studies that would yield the data necessary to guide both HIV-positive drug users and their health-care professionals in making informed treatment decisions. Trials involving illegal drugs are certainly permissible under current Canadian law. However, it may be difficult to argue that the *Canadian Charter of Rights and Freedoms* or human rights acts

require the inclusion of drug users in clinical trials of HIV/AIDS drugs.

The Report therefore recommends that:

- barriers to the participation of drug users in clinical trials be removed;
- community groups and drug users develop recruitment strategies to encourage participation of HIV-positive drug users in clinical trials;
- pharmaceutical companies take a leadership role in promoting studies that test the effect of HIV/AIDS drugs on injection drug users; and
- the Medical Research Council and pharmaceutical companies develop a comprehensive research agenda that identifies priorities in research for injection drug users.

Information about the Use and Effects of Illegal Drugs

The sixth issue studied is the provision of accurate and complete information on illegal drugs to health-care providers, drug users, and the general public. Many professionals in the health fields do not receive adequate education on drug use and the treatment of patients who use drugs. Many existing materials and programs educating youth and the general public are based on abstinence principles. The lack of (accurate) information has a negative impact on the provision of care, treatment, and support of drug users, as well as on efforts to prevent HIV infection and other harms. More programs that provide accurate, non-judgmental information are therefore required.

Legally, the development of educational material about drugs generally falls within the discretion of government health officials. It would be difficult if not impossible to use the law to address the failure to provide accurate information about illegal drugs and their effects.

Ethical principles, however, dictate that individuals in society have accurate and comprehensive information on all matters that require decision, choice, and action. In particular, for health-care professionals to honour the principles of lucidity, fidelity, and humanity, they must obtain accurate information on illegal drugs so they can best care for their patients.

The Report therefore recommends that:

- accurate, unbiased, and non-judgmental information be developed on illegal drugs for health-care providers, drug users, and members of the public;
- ministries of education and health undertake an evaluation of school programs on illegal drugs; and
- universities and colleges ensure that the curricula of health-care professionals include materials, presentations, and discussions of harm-reduction approaches to drug use.

Needle Exchange and Methadone Maintenance Treatment

The seventh, and last, issue studied is the concern that the rules and regulations governing needle exchange programs and methadone maintenance treatment programs may render these programs less effective at reaching their goals.

With regard to needle exchange programs, several barriers have been identified. There is concern that not enough needles are available to injection drug users at needle exchange sites; sometimes, individual quotas are imposed and used syringes may be required in exchange for sterile syringes. Needle exchange sites are generally located in large cities and may be centralized in these cities. Hours of operation may be restricted. Many pharmacists are reluctant to provide sterile syringes to injection drug users. All of these factors limit access to sterile syringes. Finally, persons involved in needle exchange programs as well as drug users may be criminally liable for traces of illegal drugs found in drug equipment.

With regard to methadone maintenance treatment programs, in comparison with other countries such as Australia, Switzerland, and Belgium, Canada has a low number of heroin-dependent persons who are treated with methadone. Many programs adhere to an abstinence philosophy and some do not offer comprehensive services such as primary health care, counseling, or education. In order for physicians to prescribe methadone, they must obtain federal authorization pursuant to the Narcotic Control Regulations. The provinces have the authority, which is delegated in some jurisdictions to the College of Physicians and Surgeons, to establish the rules under which physicians and patients may participate in methadone programs. Rules in methadone programs that hinder effective treatment of injection drug users include: limits on doses that may be prescribed by physicians; mandatory urine testing while being observed by staff; and restrictions on "carries" or take-home medication.

As a result of such restrictions, drug users often experience their interactions with needle exchange or methadone maintenance programs as disrespectful of their individual dignity, as invading their privacy, or as severely infringing their autonomy.

These are not only ethical concerns, but also practical barriers to achieving the objectives of such programs.

The Report therefore recommends that:

- methadone maintenance treatment programs become available to persons in all parts of Canada, including in rural and semi-urban areas, and in prisons;
- review of the methadone regulations and rules be undertaken to ensure that they are in conformity with the care, treatment, and support needs of injection drug users; and
- needle exchange programs become easily accessible to injection drug users in all parts of Canada, including in prisons.

Conclusion

Canada is in the midst of a public health crisis concerning HIV/AIDS and injection drug use, but its response to this crisis is far from being concerted and effective. Indeed, the lack of appropriate action has led some to conclude that another public health tragedy, comparable to the blood tragedy in the 1980s, is underway, illustrating that little if anything has been learned from the lessons taught by that tragedy. As Skirrow says:

> A marginalized community (in this case injection drug users) is experiencing an epidemic of death and disease resulting not from anything inherent in the drugs that they use, but more from the ineffective and dysfunctional methods that characterize our attempts to control illegal drugs and drug users. There is the same unwillingness to carefully analyze the problem or to depart from traditional methods and conventional thought that was integral to the blood tragedy. There is a struggle for power and control over the issue between law enforcement and public health. There is a profound lack of understanding among decision-makers and many health professionals regarding the nature of the community and individuals at risk.[4]

The report on *Injection Drug Use and HIV/AIDS: Legal and Ethical Issues* and the extensive consultations leading to it have shown, once again, that the legal status of drugs in Canada contributes to the difficulties encountered in addressing HIV among injection drug users. However, it also shows that much can be done now, without waiting for the much-needed legal changes, within the current legal framework; indeed, much *must* be done, as ethical analysis reveals, because current approaches do not withstand ethical scrutiny:

> It is *ethically* wrong to continue criminalizing approaches to the control of drug use when these strategies: fail to achieve the goals for which they were designed; create evils equal to or greater than those they purport to prevent; intensify the marginalization of vulnerable people; and stimulate the rise to power of socially destructive and violent empires.
>
> It is *ethically* wrong to continue to tolerate complacently the tragic gap that exists between what can and should be done in terms of comprehensive care for drug users and what is actually being done to meet these persons' basic needs.
>
> It is *ethically* wrong to continue policies and programs that so unilaterally and utopically insist on abstinence from drug use that they ignore the more immediately commanding urgency of reducing the suffering of drug users and assuring their survival, their health, and their growth into liberty and dignity.
>
> It is *ethically* wrong utterly to neglect to organize the studies needed to deliver the knowledge required to care more adequately for persons who use drugs and are HIV-infected.
>
> It is *ethically* wrong to exclude HIV-infected drug users from participation in clinical trials when that exclusion is based not on scientific reasons but rather on prejudice, discrimination, or simply on considerations of clinical-trial convenience for the investigators.
>
> It is *ethically* wrong to tailor or suppress the information about illegal drugs that individual users, professionals, and citizens generally need to know in order to act responsibly.
>
> It is *ethically* wrong to set up treatment or prevention programs in such a way that what the program gives with one hand, it takes away with the other.
>
> It is *imperative* that persons who use drugs be recognized as possessing the same dignity, with all the ethical consequences of this ethical fact, as all other human beings.[5]

Recommendations

A total of 66 recommendations, some of which have been mentioned above, are made throughout the Report. Most of these can be implemented in the short term, without

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making any radical changes to Canada's drug laws. Some are designated as longer-term, requiring changes to these laws. The recommendations are directed to those whose policies and actions (or inactions) affect Canada's ability to prevent the further spread of HIV and other infections among injection drug users, and to provide care, treatment, and support to those already living with HIV or AIDS. This includes: the federal, provincial/territorial, and municipal governments, colleges of physicians and surgeons, professional associations of health-care workers, universities, and community-based agencies. Implementing these recommendations must become an urgent priority.

This text is an edited version of the executive summary of *Injection Drug Use and HIV/AIDS: Legal and Ethical Issues*. A list of all recommendations, and the references for statements made in this summary, can be found in the report. The report, the volume of Background Papers, and the series of info sheets are available for browsing and retrieval on the Legal Network's website at <www.aislaw.ca>. They can also be obtained free of charge (postage and handling fees may apply, however, for requests from outside Canada) from the Canadian HIV/AIDS Clearinghouse. Tel: 613 725-3434; fax: 613 725-9826; email: aids/sida@cpha.ca>.

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[1] Canadian HIV/AIDS Legal Network. *Injection Drug Use and HIV/AIDS: Legal and Ethical Issues.* Montréal: The Network, 1999.

[2] Canadian HIV/AIDS Legal Network. *Injection Drug Use and HIV/AIDS: Legal and Ethical Issues. Background Papers.* Montréal: The Network, 1999.

[3] D McAmmond. *Care, Treatment and Support for Injection Drug Users Living with HIV/AIDS: A Consultation Report.* Ottawa: Health Canada, March 1997; Task Force on HIV, AIDS and Injection Drug Use. *HIV, AIDS, and Injection Drug Use: A National Action Plan.* Ottawa: Canadian Public Health Association & Canadian Centre on Substance Abuse, 1997.

[4] J Skirrow. Lessons from Krever – A Personal Perspective. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(2/3): 35-41 at 40-41.

[5] D Roy. Injection Drug Use and HIV/AIDS: An Ethical Analysis of Priority Issues. In: *Injection Drug Use and HIV/AIDS: Legal and Ethical Issues. Background Papers.* Montréal: Canadian HIV/AIDS Legal Network, 1999.

Newly Infected People & Clinical Trials: Ethical Issues

cont'd from page 1

The Reality for Newly Infected People

The reality for newly infected people is totally different. While still in shock from the diagnosis and totally inexperienced with the world of HIV/AIDS, and while not at risk of death in the short term, they are under pressure to decide quickly about treatment. They must be able to answer two very difficult questions: Should I start antiretroviral therapy now? Should I participate in the clinical trial that my physician is suggesting? They have to be able to answer these two questions while they are still disoriented and often have only the medical team to consult with.

In our view, newly infected people definitely constitute a vulnerable population, since the emotional shock they are experiencing diminishes their decision-making capacity. Their vulnerability is exacerbated by the fact that the populations being infected are increasingly the poor, less educated, and more marginalized groups in society. An ever larger number come from the most disadvantaged and poorest segments of society. Many are teenagers or young adults, and many have a very low level of literacy. Researchers therefore have additional ethical obligations toward these vulnerable individuals, obligations that must take the form of special procedures that ensure their right to a truly informed consent process.

Key Information

To identify such procedures, we must first establish what key information needs to be given to newly infected potential participants in clinical trials. The key information is greater in quantity and more complex in nature than the information usually given to clinical trial participants. To be able to give truly informed consent, newly infected people need a "crash course" in all aspects of living with HIV and controlling the virus. This must incorporate complicated information about treatment issues and medical aspects of HIV, and must also include basic practical information about living with HIV and about avoiding discrimination.

Newly infected people need information on the rationale behind early intervention and on the consequences of delaying the decision to start therapy. They must have access to statistics showing that, following the acute-infection phase, many people can expect to live for many years without symptoms. They must understand the commitment they are making when they decide to start therapy. They must understand that no one knows how long such a commitment needs to be or whether it is possible to stop treatment and, if so, when. They have to understand the importance of compliance and the difficulty

of complying even where they have never been ill and/or faced the possibility of dying as a result of an opportunistic infection. They must also recognize that information about long-term adverse side effects is emerging and will continue to emerge over time.

The consequences of being on antiretroviral therapy must be explained. It is difficult to hide the fact of having to take so many pills, and difficult to hide their side effects. Cost issues must be explained. In certain provinces, such as Québec, medications are not totally free. The cost and the initial financial outlay required depend on income or employment status and the insurance coverage provided. It may be hard to hide HIV status from an employer, since for most workers the refundable portion must be claimed from a group-insurance plan.

Necessary Changes to Enrolment Procedures

All this information must be provided to and understood by the prospective participant in order for the person to make the first decision: "Should I start therapy now?" When added to the usual specific details about the trial, this results in an enormous amount of information that could mean an extremely long and complex text that the participant might not be able to read or understand fully. We must recognize that it is difficult and takes time to digest so much information. Therefore, researchers and research ethics boards have to explore new ways to transmit information during the trial-enrolment procedure.

A number of solutions are feasible. The introduction of an obligatory information session (or sessions, if needed) with an independent counselor is one viable solution. Other information tools must be considered, including videos on various aspects of living with HIV and on controlling the virus. It is not enough to provide the phone number of an existing information resource, since the newly infected person may not be ready to make such a call on their own.

Conclusion

Researchers and clinical-trial sponsors studying early intervention must propose innovative procedures to support decision-making by newly infected people. These procedures must undergo ethics review. They must address the issues of providing medical and practical information, and the need for psychological support. Otherwise, truly informed consent cannot be obtained from prospective participants.

Researchers and clinical trial sponsors studying early intervention must propose innovative procedures to support decision-making by newly infected people.

- Jean-Pierre Bélisle & Louise Binder

This article summarizes an oral presentation made at the 8th Annual Canadian Conference on HIV/AIDS Research in Victoria, British Columbia, in May 1999. Jean-Pierre Bélisle and Louise Binder are both people with HIV/AIDS who have been active in HIV/AIDS advocacy for a number of years, with a particular interest in treatment advocacy. Jean-Pierre is presently a researcher at the École des Hautes Études Commerciales in Montréal, and Louise is Co-Chair of the Canadian Treatment Advocates Council. Jean-Pierre can be reached at <Jean-Pierre.Belisle@hec.ca>, Louise at <lbinder@attcanada.net>.

HIV/AIDS IN CANADIAN COURTS

HIV/AIDS in Canadian Courts in 1999: Part 1

This column presents a summary of miscellaneous Canadian court cases in January to May 1999 relating to HIV/AIDS. A review of 1998 cases was included in the last issue of the *Newsletter,* and subsequent cases will be summarized in future issues. A search of Canadian electronic legal databases yielded several cases reported in January to May 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 access to medical marijuana, assisted suicide, and developments in litigation over tainted blood or blood products. Criminal cases (both in Canada and other jurisdictions) are summarized elsewhere in this issue.

Medical Marijuana: Update on the Wakeford Case

In May 1999 LaForme J of the Ontario Superior Court of Justice granted Jim Wakeford, an HIV-positive Toronto man, an "interim constitutional exemption" from the provisions in the *Controlled Drugs and Substances Act*[1] that make it an offence to possess or to produce or cultivate marijuana (*cannabis sativa*).[2]

As reported in the last issue of the *Newsletter,* in February 1998 Wakeford had brought an application to court, arguing that the prohibition on possession and cultivation of marijuana violated his Charter rights to equality as a person living with the disability of HIV (s 15) and to "life, liberty and security of the person" (s 7). He also sought an order that the federal government provide him with a secure supply of marijuana for medicinal purposes.

In September 1998[3] LaForme J ruled that the violation of Wakeford's right to liberty and security of the person was not contrary to "principles of fundamental justice" because the Act allowed the Minister of Health to exempt any person or any controlled substance if it were "necessary for a medical or scientific purpose or is otherwise in the public interest" (s 56). The Court found that Wakeford had not applied to the Minister for an exemption before seeking a constitutional remedy from the courts. It therefore dismissed his application. At the same time, however, it ruled that

> if there is no real process or procedure whereby an individual in the situation of Mr Wakeford could seek to be exempt from the application of the CDSA, that would be contrary to the principles of fundamental justice. If that were the case, I would have no hesitation in granting, perhaps even all, the relief Mr Wakeford seeks.[4]

In March 1999 Wakeford sought a rehearing of his application on the basis of new developments. In May further evidence was presented to LaForme J by a representative of the Bureau of Drug Surveillance (Health Canada). Based on the additional evidence, the Court concluded: "While an exemption process for persons like Mr Wakeford may have been reasonably viewed as a possibility at the original hearing, it was, as was suggested at that time [by Wakeford], in fact illusory."[5] In the Court's view, "had Mr Wakeford formally applied for an exemption, the Minister of Health had no real and meaningful way of considering his application."[6]

LaForme J also concluded from the additional evidence that the federal government is still in the process of devising a process for considering "section 56 applications" for exemptions from prosecution under the CDSA:

> However, I find that the significance of the evidence is not what it demonstrates, but rather, what it fails to demonstrate. That is, it is now clear that where there was no process to consider any s 56 CDSA applications, there now is. Regrettably the evidence is clear that it is unknown whether or not the process can work or even if it is capable of doing so, and if so, can it do so in a meaningful and timely fashion.

Given that Wakeford's application is "bona fide, for a legitimate medical purpose, and one which merits genuine consideration" by the Minister, LaForme J granted to Wakeford an "interim" constitutional exemption from the possession and cultivation sections of the CDSA until there is a decision on his application by the Minister of Health.

At the end of May 1999, the federal Minister of Health announced that clinical trials on the medicinal benefits of marijuana will proceed, and that the government would seek to establish a growing facility in Canada to provide marijuana of consistent quality for this research.[7] In June the Minister announced that the first set of trials will examine the benefits of smoked marijuana for people with HIV/AIDS, and will be conducted by the Community Research Initiative of Toronto and the HIV Trials Network. Other trials will test a liquid version of THC (the active ingredient in cannabis), and will study the benefits for those with illnesses other than HIV/AIDS.[8]

At the end of May 1999, the federal Minister of Health announced that clinical trials on the medicinal benefits of marijuana will proceed.

Assisted Suicide and Physician Misconduct: Sentence Upheld

In a 27 April 1999 decision, the Ontario Court of Appeal upheld the original sentence imposed on Toronto physician Maurice Genereux on two counts of aiding and abetting a patient to commit suicide.[9] In 1995 Genereux supplied two of his HIV-positive patients (not diagnosed as having AIDS) with lethal doses of the drug Seconal, at their request. Genereux knew that both patients were seriously depressed (but not terminally ill), that both were contemplating suicide, and that treatment could have helped both. Both patients overdosed. The first patient was discovered by a friend shortly after ingesting the Seconal and was hospitalized; he survived. The second patient was also discovered by a friend; upon calling Genereux, the friend was told not to call an ambulance. This second patient died.

After 11 days of evidence at a preliminary inquiry, Genereux pleaded guilty to these charges. Charges of criminal negligence (causing death in one case, and causing bodily harm in the other) were dropped. Genereux was sentenced to imprisonment for two years less a day and three years' probation on each count, to be served concurrently.[10] He appealed the sentence; the Crown cross-appealed, seeking a longer prison term. The Council of Canadians with Disabilities intervened.

The Ontario Court of Appeal declined to accept the Crown's arguments that the principles of deterrence and denunciation required a harsher sentence. The Court held that Genereux' conduct was

> a complete departure from acceptable medical standards and ethics, and it should be treated as such. The case stands on its own facts. We are sure that for such conduct the certainty of the loss of professional status, prosecution and incarceration where appropriate is understood.

The Court therefore declined to increase the sentence so as to "intimidate physicians in the appropriate treatment of their patients." The Court also felt that the need for denunciation had been adequately recognized, noting that "the offences were not committed for financial gain or personal benefit nor were they committed for the purpose of making a public or political statement about euthanasia or assisted suicide." Rather, the Court found they resulted from Genereux' "very serious personal inadequacies and his misguided acceptance of doing what his patients wanted him to do." However, the Court also rejected Genereux' claim that he should serve his sentence in the community, saying that a prison term is "required to mark society's condemnation" of his conduct. The original sentence was affirmed.

Developments in Litigation over Contaminated Blood

Appellate court affirms Red Cross liability for negligent donor screening

In March 1999 the Ontario Court of Appeal issued its joint ruling in two cases against the Canadian Red Cross Society (CRCS) for negligence in donor screening in the mid-1980s. The two cases, *Osborne*[11] and *Walker*,[12] had been tried together; the trial court's judgment in both was issued in 1997.

The written material and questionnaire used by the Red Cross at the time of this donation "did not constitute a reasonable measure to protect the safety of the blood and blood products."

In *Osborne,* the plaintiff was infected in January 1985 through blood plasma from blood donated in December 1984 by a sexually active gay man with multiple partners, who had been unaware of his HIV-positive status. Relying heavily on the screening practices then in place in the US, trial judge Borins J found that the written material and questionnaire used by the Red Cross at the time of this donation "did not constitute a reasonable measure to protect the safety of the blood and blood products provided by the CRCS" because it did not identify any of the well-known symptoms of AIDS or caution people with such symptoms against giving blood. In light of this negligence by the Red Cross, the trial judge ruled in favour of Mr Osborne. The Ontario Court of Appeal upheld this judgment.

However, the trial judge reached a different conclusion in the Walker case, and this case was also before the appellate court. The Walker case dealt with events that happened at an earlier time. The plaintiff was infected in October 1983 through transfusion of red blood cells donated in September 1983, again by a sexually active gay man with multiple partners. The trial judge made no final finding as to whether the Red Cross was negligent for not implementing adequate donor-screening measures in September 1983. However, he concluded that, even if the Red Cross had failed to take adequate measures, the plaintiff had not proved that the donor of the contaminated blood would have been deterred from donating by such proper screening measures. He therefore ruled against Ms Walker.

On appeal, the Ontario Court of Appeal overturned this decision. It stated that it had "no difficulty" in finding that the CRCS failed to implement a program at donor clinics to screen out "high risk" individuals and that it "knew or ought to have known that its failure to implement adequate screening measures could result in the transmission of HIV infected blood to innocent recipients such as Mrs Walker."[13] Having made these findings, the Court of Appeal also concluded that the trial judge had erred in requiring the plaintiff to also prove that the screening measures would have deterred the donor. Citing a Supreme Court of Canada decision in which a plaintiff suing for injuries caused by breast implants was confronted with a similar argument,[14] the Court stated that

> requiring the plaintiff to prove a hypothetical situation relating to the conduct of the infectious donor could, in some instances, make it virtually impossible for the plaintiff to prove causation.... In our view, as a matter of policy, it would be unjust to allow the CRCS to escape liability by placing what, in some cases, could amount to an impossible burden on an innocent plaintiff.... Fault, as understood in tort law, does not require that the Walkers overcome the additional burden of proving what some other person would have done had the CRCS acted in accordance with its duty to Mrs Walker.[15]

The Court of Appeal therefore overturned the trial court's decision and granted judgment for the plaintiff.

The result of these decisions is to secure, at the appellate level, the finding that – at least up to March 1985 – the CRCS was negligent in failing to implement adequate measures to screen out potential blood donors at "high risk" of being HIV-positive.

Alleged Red Cross negligence for blood-clotting products must be litigated

In January 1999, in three cases brought by (now deceased) HIV-positive hemophiliacs against the CRCS, an Ontario trial court ruled that the issue of the Society's negligence must be litigated. The plaintiffs in *Robb, Rintoul,* and *Farrow*[16] alleged the Red Cross was negligent in its screening of blood donors, resulting in the plaintiffs' infections from clotting product (Factor IX concentrate) used to control their hemophilia. Relying on findings by the trial judge in the earlier cases of *Osborne* (discussed above) and *Vos,* the plaintiffs asked the court to order that the Red Cross be prevented ("estopped") from disputing its negligence in the current cases. The court distinguished those earlier cases as involving a different factual basis, and dismissed the plaintiffs' motion.

As noted above, in *Osborne*, in a passage subsequently cited and approved by the Ontario Court of Appeal, an Ontario trial court had ruled that the Red Cross

> owed a duty of care to users and recipients of blood and blood products to take reasonable measures to protect the safety of the blood, and blood products, it provided for therapeutic use.... In general terms, the duty of care required of the CRCS was to determine the extent of the risk of TAA ["transfusion associated AIDS"], to warn users and recipients of blood of the extent of the risk and to take appropriate measures to minimize, or eliminate, it. Thus, because of the magnitude of the risk and the magnitude of the consequences to persons who might suffer as a result of the use, or transfusion, of contaminated blood, or blood products, the duty of care was a high one.[17]

Borins J found that, given the medical evidence available at the time (December 1984 through March 1985), the Red Cross had failed to meet the standard of care in donor screening required of a blood collector. (As noted above, in March 1999 the Ontario Court of Appeal affirmed this judgment.)

In the subsequent *Vos*[18] case, a teenager infected with HIV as a result of receiving blood during heart surgery in March 1985 alleged negligence by the Red Cross in its donor screening and its failure to warn him of the risk to him as a recipient of donated blood. The Ontario trial judge in this case ruled that the plaintiff was entitled to rely upon these findings from the *Osborne* case and was not required to re-litigate the issue of whether the Red Cross had been negligent.

However, MacDonald J of the Ontario Court (General Division) ruled that the question raised by the *Robb, Rintoul* and *Farrow* cases is not the same question as was decided in the *Osborne* and *Vos* cases. MacDonald J ruled that the facts relevant to the production and distribution of the blood concentrate at the time of these plaintiffs' infection (in mid-1985) are different from the questions related to transfusions of blood. The product is created by pooling thousands of units of blood plasma, rather than transfusion from discrete, identifiable donors whose membership in a "high risk group" might be determined. At the time, the Red Cross did not have its own fractionation facilities, but rather shipped Canadian-sourced blood to US manufacturers. MacDonald J therefore concluded:

> *Osborne* decided the question of the standard of care expected of the Red Cross in Canada in late 1984 and early 1985 to protect patients from transfusion associated AIDS (TAA) from high risk donors. The reasons of Borins J [in that case] do not speak to the myriad of issues raised ... [by the] defence of the Red Cross in this action. Similarly, his reasons do not speak to complex legal and factual issues which are inherent in the collection, collation, manufacture, trans-border shipment and timing of distribution of unheated and heated blood products for the use of hemophilia patients. *Osborne* does not deal with the question of the adequacy of screening methods to prevent HIV being passed into the blood system from persons who were not members of identified high risk donor groups. Finally, it is not apparent at this, the beginning stage of this trial, whether possible dates of donation of allegedly infected blood correspond to the time period analyzed in *Osborne.*

As a result, MacDonald J dismissed the plaintiffs' motion, requiring the question of Red Cross negligence with respect to the distribution of unheated blood products during this time period to be fully litigated at trial.

- Richard Elliott

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[1] SC 1996, c 19.

[2] *Wakeford* v *Canada*, [1999] OJ No 1574 (10 May 1999) (QL) (Gen Div).

[3] Note: The date of this earlier decision was incorrectly reported as August 1998 in the last issue of the *Newsletter.*

[4] *Wakeford* v *Her Majesty the Queen*, unreported, released 8 September 1998, at 26 (Ont Ct Gen Div), LaForme J.

[5] *Wakeford* v *Canada*, supra, note 2, at para 11 (QL).

[6] Ibid at para 8 (QL).

[7] T Harper. Commons a-buzz over grown-in-Canada pot. *Toronto Star*, 28 May 1999, A2; M Kennedy. When it comes to medicinal pot, Rock favours using home-grown. *National Post*, 28 May 1999, A4.

[8] A McIlroy. Canadian companies can soon bid to grow pot for medicinal use. *Globe and Mail*, 9 June 1999, A3.

[9] *R* v *Genereux,* [1999] OJ No 1387 (CA) (QL).

[10] *R* v *Genereux,* unreported, Sentence Hearing, 13 May 1998, Ontario Court (Gen Div), Scullion J.

[11] *Osborne* v *Canadian Red Cross Society et al*, (1997), 39 CCLT (2d) 1 (Ont Ct Gen Div), aff'd [1999] OJ No 644 (QL) (CA).

[12] *Walker Estate* v *York Finch General Hospital*, (1997) 39 CCLT (2d) 1 (Ont Ct Gen Div), rev'd [1999] OJ No 644 (QL) (CA).

[13] Ibid at para 35 (QL) (CA).

[14] *Hollis* v *Dow Corning Corp* (1995), 129 DLR (4th) 609 (SCC).

[15] Walker Estate, supra, note 12, at paras 45-48 (QL) (CA).

[16] *Robb* v *St Joseph's Health Care Centre et al*; *Rintoul* v *St Joseph's Health Care Centre et al*; *Farrow* v *Canadian Red Cross Society et al*, [1999] OJ No 177 (Gen Div) (QL).

[17] *Osborne*, supra, note 11 at 57-58 (Gen Div).

[18] *Vos* v *Canadian Red Cross Society*, [1998] OJ No 4369 (Gen Div) (QL); R Elliott. HIV/AIDS in Canadian courts in 1998: an overview. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(2/3): 9-12 at 12.

TESTING AND CONFIDENTIALITY

The HIV Test Experience Study

For many reasons, HIV remains different from other diseases. This also means that, for many of those taking the HIV test, this continues to be a difficult experience, despite recent tendencies to "banalize" HIV testing. The study described below provides a more comprehensive understanding of the meaning of the test within different subgroups, and of the implications of taking the test and receiving results. It makes recommendations on how to improve current testing and counseling practice.

Background

Voluntary HIV-antibody testing was initiated in Canada in 1985. Counseling has been considered an important component of this service. Although outcome measures such as the number of individuals testing, risk behaviours, and prevalence of positive tests had been compiled, little was known about the processes and variations that occur in testing. In the literature, information about HIV testing comes predominantly from cross-sectional and administrative survey questionnaires. These methods are generally concerned with understanding a broad range of social and behavioural issues related to HIV-antibody testing and counseling, knowledge of HIV/AIDS, and reasons for and attitudes to testing. A small but growing number of in-depth studies in the HIV test literature are moving away from describing outcomes of HIV testing and counseling to explore the meaning behind taking the HIV-antibody test, decision-making, communication processes, and social and emotional impacts of the experience.

This study was prompted by the need for a more comprehensive understanding of the meaning of the test within different subgroups, and of the implications of taking the test and receiving results. This perspective was considered important for the development of HIV counseling programs and policies, and to provide a structure as well as a basis for further research and evaluation.

Purpose of Study

The major goal of this study was to describe and analyze HIV pre- and post-test counseling, specifically:

- to describe what information is provided by test providers and received by test recipients in the pre- and post-test HIV test encounter;
- to analyze variations in the processes and content of HIV pre- and post-test counseling;
- to describe variations in knowledge and concepts brought to the counseling situation by the test provider; and
- to analyze test recipients' appraisals of the HIV test experience.

Design of Study

The study was undertaken in Ontario, where three test reporting protocols (nominal, non-nominal, and anonymous) are practised. In the design of this study, qualitative methods were selected in order to delineate a broad spectrum of HIV-antibody test experiences. The investigators sought to include both HIV test providers and recipients. Interviews, with open-ended questions, were conducted, audio tape–recorded, transcribed verbatim, and analyzed using qualitative data management software.

HIV test providers were recruited from different testing venues, including STD clinics, HIV care programs, and venues that attract specific test-recipient groups, for example, gay men, street youth, women, and injection drug users. Twenty-four HIV test providers were interviewed. There were fifteen counselors from Ontario's anonymous testing program, and nine physicians. Forty-one HIV test recipients, both male and female, were interviewed for the study, with close to equal numbers

who tested HIV-positive and HIV-negative.

The questions in the test-provider schedule asked for descriptive information about the objectives, components, and limitations of HIV testing. Those in the test recipients' schedule focused more on the experience of the HIV test and critical appraisals of it.

For the analysis, the HIV test experience was not regarded as a single event, but as a series of specific elements:

- the HIV pre-test situation;
- the HIV pre-test encounter;
- the waiting period between the pre-test encounter and post-test encounter;
- the encounter in which the result is disclosed; and
- the impact of the HIV test experience (the cognitive, emotional, and behavioural impact of the test on the test recipient and test provider).

In the presentation of results, verbatim quotations from the interviews are the primary mode for reflecting the participants' experiences.

HIV Test Recipients' Descriptions of Reasons for Testing

Both HIV-positive and HIV-negative test recipients acknowledged that they had engaged in risk behaviour. Many test recipients gave more than one reason for being tested. Reasons given were grouped into categories: risk behaviour; social identification with risk; personal influences; desire for knowledge about HIV status (routine, confirmatory, psychological, or third party); and illness or symptoms. A number of test recipients also acknowledged social risks – for example, being a man who has sex with men or being an injection drug user. Testing was also influenced by a test recipient's relationships with others – for example, the influence of family or doctors or by past relationships. Some wanted to know their HIV status because of "AIDS anxiety." For many, the test was a routine health practice; for others it was confirmation of a previous positive test result. Illness, symptoms, or infection were precipitating factors in being tested.

Test Providers – Training and Best Practices

None of the physicians in this study reported having any formal training in HIV/AIDS. In every case the physicians learned about HIV and HIV-related medicine on the job, through mentorship, and by reading medical journals, clinical trial reports, or other HIV-related materials. Anonymous test providers were trained in a variety of occupations. These included social work, public health, nursing, and health education. All had received extensive training in HIV test counseling through the Ontario Ministry of Health, AIDS Bureau.

Physicians and anonymous test providers identified their best practices and professional principles in the conduct of their HIV test protocols. The best practices and principles identified by physicians and anonymous test providers were similar and reflect a process of acculturation to work in the HIV field.

Appraisals of the Test Experience

Both test providers and test recipients provided appraisals and critiques of their experience. The most varied appraisals were from the test recipients, many of whom compared good and bad experiences. The appraisals were based on the various expectations that recipients brought to the test experience. Test recipient appraisals centred on the provider and the test environment. Test recipients universally valued confidentiality and preferred anonymity.

Test recipients universally valued confidentiality and preferred anonymity.

> I was tested pretty much in the open, in a small cubicle. And, with questions being asked, I am sure that people could hear and that bothered me ... the privacy.
>
> It was very private, professional, courteous and understanding. I didn't feel I was being judged for being gay.
>
> My needs were never asked. I never remember being asked, "What do you need?"
>
> The way he handled the information as far as imposing his own value system on who I am became uncomfortable.
>
> I felt the most intense shame of what I'd become, what had become of my life. I would rather have died at that moment than to have to experience the hatred I felt from her. Her disgust was blatant and rude.

Recommendations

The recommendations that arose from the study findings were developed through discussions with the advisory group. These recommendations are directed to test providers, AIDS service organizations, provincial policy-making bodies, professional associations and educators in continu-

ing education, and professional schools and faculties within universities and colleges. The recommendations related to program improvements and enhancements, as summarized below:

- Individuals who present for the test or who are advised to be tested should be informed about all test protocols available in a province, and how to access each.
- Test environments should be assessed and modifications should be made in order to be sensitive to test recipients' needs and to ensure privacy and confidentiality.
- In the risk assessment, (a) criteria for interpretation of risk should be clarified and (b) mechanisms should be developed to assist test recipients in their own risk assessment.
- In repeat test encounters, where providers do not perceive the person to be at risk for HIV infection, an individual's request for the test should be respected and carried out, and the individual should be referred for further counseling and support, if appropriate.

Partner notification should be explained and discussed in the pre-test encounter and not restricted to the post-test encounter.

- Partner notification should be explained and discussed in the pre-test encounter and not restricted to the post-test encounter.
- Mechanisms should be developed to extend counseling resources to test recipients in the waiting period between the pre-test and post-test encounter.
- To reduce the waiting period, laboratory mechanisms that accelerate testing should be developed.
- There should be evaluation of emerging rapid testing procedures and mechanisms, and of the effect of these on the test recipient and provider.
- Where possible, pre-test counseling and post-test counseling should be provided by the same individual.
- Opportunities for additional counseling (multiple sessions) should be made available to people who test HIV-positive and to their partners and families.
- Printed materials should be made available to persons who test HIV-positive in the post-test encounter. These should include: the telephone numbers of provincial HIV/AIDS toll-free help lines, the telephone numbers and addresses of the local community-based AIDS service organizations or an appropriate health clinic, information on how to access an appropriate primary care physician, a generic pamphlet that contains basic information in accessible language about safer sex, safer injection, diet, avoidance of negative drug interactions and partner notification, a brochure on support programs, for example drug benefit plans, basic information on treatment protocols and how to get up-to-date information on these.

Several recommendations also were made concerning the review of current practices and procedures.

- HIV test guidelines should be reviewed in the context of best practices and principles related to self-determination, test protocol options, and affirmative action.
- HIV test guidelines should be reviewed in the context of emerging issues: providing test results over the telephone, access to testing and quality service in low-volume and remote areas, injection drug use, and screening of pregnant women.

Additional recommendations were made that concerned training courses, curricula, and content of HIV education in colleges and universities that provide professional education and continuing education; as well as support requirements and programs for test providers.

The HIV epidemic and responses to it remain dynamic; HIV testing techniques and attitudes to then continue to evolve. The study has suggested that in spite of these facts the disease continues to present issues, many of which relate to stigmatization. To maintain and improve the effectiveness of the test as a prevention and treatment intervention, it is important to continue to evaluate the impact of the HIV test on recipients and providers, as well as to understand the impact of systemic changes in societal attitudes, policies, and laws.

– Ted Myers & Dennis J. Haubrich

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D Mahoney, C Worthington, and K Ryder – wish to express their appreciation to all who contributed to the study. We especially thank the test recipients and test providers who participated in the study, the advisory group members (David Browne, Mary Dyson, Carol Major, Brenda Perkins, Michael Sobota, Janis Tripp, Robert Trow, Evelyn Wallace), staff of the recruitment sites and staff of the AIDS Bureau, Ontario Ministry of Health.

Copies of the study report (T Myers et al. *The HIV Test Experience Study*. Toronto: HIV Social, Behavioural and Epidemiological Studies Unit, Faculty of Medicine, University of Toronto, 1998) may be obtained from the Canadian HIV/AIDS Clearinghouse. Tel: 613 725-3434; fax: 613 725-1205; email: <aids/sida@cpha.ca>.

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US – Phony Test Kits

On 17 February 1999 a California man was sentenced to 63 months in federal prison after being convicted of marketing phony HIV test kits for home use.

Larry Green received the maximum sentence allowed for five counts of mail fraud and 11 counts of wire fraud involving a scheme to market medically useless test kits over the Internet and through more than 30 local pharmacies.[1]

Green represented the kits as "confidential, safe, accurate and easy to use," even though they had not been approved by the Food and Drug Administration (FDA), as required by law. The FDA recalled the devices in December 1997 and opened a criminal investigation.

US District Judge Robert E Coyle said he applied the maximum penalty because Green showed no remorse and his conduct was extreme in view of the emotional harm he caused his customers. About 30 people had purchased the kits.

[1] Reported in *AIDS Policy & Law* 1999; 14(4): 12.

POST-EXPOSURE PROPHYLAXIS

Currently, post-exposure prophylaxis (PEP) is available almost exclusively to persons who may have been exposed to HIV in the health-care occupational setting. The ethical and legal acceptability of this practice is now being challenged on the grounds that all persons who may have been exposed to HIV should have equal access to preventive treatment, regardless of the source, the setting (for example, occupational/non-occupational), or the nature of the potential exposure (for example, the route of transmission and the severity of exposure). We reprint here the most relevant sections of an article originally written for the "National Conference on HIV Post-Exposure Prophylaxis in the Non-Occupational Setting: Decision-Making in the Face of Uncertainty," held in Toronto on 23-24 October 1998, and since published in *AIDS & Public Policy Journal* 13; 3: 106-133. The article first calls into question the underlying assumption that PEP for HIV is a sufficiently safe and efficacious preventive treatment, pointing out that PEP for possible exposure to HIV, regardless of the source and nature of exposure, is most appropriately viewed as a non-validated practice requiring further research. It then analyzes various questions relating to funding, access, informed choice, confidentiality, and liability for PEP. It concludes by suggesting that, while maintaining the status quo – according to which PEP is available mostly to persons with possible health-care occupational exposures to HIV – does not appear to be an option, simply amending current policies to cover PEP for all possible exposures to HIV should be avoided. It suggests a number of questions that policy-makers should consider when working to improve current policies.

Expanding Access to Post-Exposure Prophylaxis: Ethical and Legal Issues

This article examines, from a Canadian perspective, the legal and ethical issues relating to post-exposure prophylaxis (PEP) for possible non-occupational exposure to HIV. Of primary concern is the risk of HIV transmission through sexual contact (for example, victims of sexual assault, individuals who engage in consensual unprotected anal or vaginal intercourse) or penetration of the skin (for example, injection of drugs, tattooing, and so on using unclean equipment).

The focus of this article is on issues relating to funding, access, informed choice, confidentiality, and liability for PEP. First, however, the differences between research, non-validated practice, and standard practice are reviewed and the underlying assumption that PEP for HIV is a sufficiently safe and efficacious preventive treatment is called into question.[1]

Research, Non-Validated Practice, or Standard Practice?

Currently PEP is available almost exclusively to persons who may have been exposed to HIV in the health-care occupational setting. The ethical and legal acceptability of this practice is now being challenged on the grounds that all persons who may have been exposed to HIV should have equal access to preventive treatment, regardless of the source, the setting (for example, occupational/non-occupational), or the nature of the potential exposure (for example, the route of transmission and the severity of exposure). In researching this issue, it quickly

became apparent that the debate about expanded access to PEP rests in part on a critical assumption made by some: namely, that the use of PEP for possible occupational exposures to HIV is a sufficiently safe and effective preventive treatment. This assumption informs the claim about unjust discrimination in denying PEP to persons potentially exposed to HIV on the basis of a morally irrelevant consideration (for example, the setting in which exposure occurred). This assumption is controversial.

Anecdotal experience, a retrospective case-control study of PEP for health-care workers,[2] the findings from the ACTG 076 study on the effects of zidovudine (ZDV, AZT) on perinatal HIV transmission,[3] and some animal studies[4] suggest that zidovudine may be an efficacious preventive treatment for persons potentially exposed to HIV. On the basis of this limited data, some physicians seeking to provide care for their patients have been prescribing an antiretroviral drug regimen (a monotherapy regimen or a combination regimen)[5] they believe to be an efficacious prophylaxis.[6] Indeed, according to some, this is now the standard of care for health-care workers (for example, physicians, nurses, laboratory technicians) who have possible occupational exposures to HIV.[7]

This practice and other factors have led governments and others to ask questions about funding, access, liability, and other issues relating to PEP for all persons possibly exposed to HIV, regardless of the setting in which the exposure may have occurred. Answering these questions in a responsible manner, however, requires serious deliberation about a prior question, namely whether PEP is research, non-validated practice, or standard practice.

> The term "research" refers to a class of activities designed to develop or contribute to generalizable knowledge. Generalizable knowledge consists of theories, principles or relationships (or the accumulation of data on which they may be based) that can be corroborated by accepted scientific observation and inference.
>
> The "practice" of medicine ... refers to a class of activities designed solely to enhance the well-being of an individual patient or client. The purpose of medical ... practice is to provide diagnosis, preventive treatment, or therapy. The customary standard for routine and accepted practice is a reasonable expectation of success. The absence of validation or precision on which to base such expectation, however, does not in and of itself define the activity in question as research.
>
> ... A practice might be nonvalidated because it is new; i.e., it has not been tested sufficiently often or sufficiently well to permit satisfactory prediction of its safety or efficacy in a patient population ... [or] because in the course of its use in the practice of medicine there arises some legitimate cause to question previously held assumptions about its safety and efficacy. It might be that the practice was never validated adequately in the first place ... or ... a question has been raised of a previously unknown serious toxicity.[8]

In addition to differences in knowledge about safety and efficacy among research, non-validated practice, and standard practice, there are also important differences with respect to objectives, target populations, and professional consensus. The last of these features is particularly relevant:

> with clinical practice there is a "professional consensus" as to the therapeutic merits of the treatment. With clinical research ... there is honest professional disagreement about the relative therapeutic merits of alternative interventions. The aim of the research is to resolve this dispute.... [W]ith non-validated practice there is honest belief on the part of some members of the profession [a respectable minority] about the therapeutic merits of the new drug, device or procedure. In time, this may give rise to honest professional disagreement.[9]

In sum, despite a shared therapeutic intention, "non-validated practices" are by definition distinct from "practice," owing to the absence of sufficient reliable data about safety and efficacy and the lack of consensus among practitioners possessing the relevant expertise about the therapeutic merits of the intervention (that is, the intervention has "neither been accepted nor discredited by the expert clinical community").[10] This is not to deny that much of current "practice" is in fact non-validated, but rather to highlight this as a danger to be avoided.[11] Ideally, an intervention should not move from the realm of "non-validated practice" to "practice" without validation.

Because PEP is currently provided in a treatment context to health-care

Data regarding the safety of PEP are incomplete, and definitive evidence of its efficacy is lacking, as is professional consensus regarding its therapeutic merits.

workers with potential occupational exposure to HIV, and not in a randomized controlled trial,[12] there is the tendency to presume that it is a safe and efficacious preventive treatment. In fact, however, data regarding the safety of PEP are incomplete, and definitive evidence of its efficacy is lacking, as is professional consensus regarding its therapeutic merits.[13] Attention to these facts is important, as history reminds us that patients can be harmed by well-meaning physicians. Consider the following notorious example. In the 1950s antibiotics were routinely administered to premature infants who were believed to be at risk of bacterial sepsis, until a study by Burns et al[14] concluded that administering penicillin and streptomycin gave no benefit to these infants and might "not be harmless."[15] The effect of a third antibiotic was more chilling; the groups of infants given chloramphenicol had "significantly higher"[16] mortality rates, and the researchers concluded that "chloramphenicol in the dosage used must have been responsible for the increase in mortality observed".[17]

The dangers in following clinical instincts and impressions, and in extrapolating from animal studies or from experience with different patient populations, can be significant. The fact that zidovudine is effective in treating acute HIV infection and in limiting perinatal HIV transmission does not necessarily mean that zidovudine alone or in combination with other drugs is a safe and efficacious prophylaxis – encouraging animal studies on the pathophysiology of HIV infection[18] and some current professional opinion notwithstanding.

The most recent Public Health Service Guidelines published by the Centers for Disease Control and Prevention (CDC) in the US frankly acknowledge the limitations of the available scientific evidence on PEP for possible exposure to HIV:

The dangers in following clinical instincts and impressions, and in extrapolating from animal studies or from experience with different patient populations, can be significant.

> The limitations of all of these studies must be considered when reviewing evidence of PEP efficacy. The extent to which data from animal studies can be extrapolated to humans is largely unknown, and the exposure route from mother-to-infant HIV transmission is not similar to occupational exposures; therefore these findings may not reflect a similar mechanism of ZDV prophylaxis.... Although the results of the retrospective case-control study of HCWs suggest PEP efficacy, the limitations of that study include the small number of cases studied and the use of cases and controls from different cohorts.[19]

Additional potential limitations with the study involving health- care workers include possible reporting bias and ascertainment bias.[20] More generally (and perhaps most important), a retrospective case-control study is not an optimal study design for evaluating the efficacy of PEP. With this type of study there is a higher risk of error, and so a lower level of evidence on the basis of which to make policy recommendations with confidence.[21]

Taken together, this all suggests that PEP for possible exposure to HIV (regardless of the source and nature of exposure) is most appropriately viewed as a non-validated practice that "should ... be made the object of formal research at an early stage in order to determine whether [it is] safe and effective."[22] In research, the "gold standard" is the randomized controlled trial because of the high level of confidence researchers can have in the validity of the results (absence of error); "it is the most effective and efficient means available to pursue the central purpose of biomedical research in the field of therapeutic innovation ... [namely,] to develop therapies that will accomplish the goals of curing or preventing diseases or of ameliorating their manifestations."[23] And, more precisely, when there is no accepted therapy or intervention, the "gold standard" is the placebo-controlled randomized trial.[24]

For both scientific and ethical reasons, many believe that it is not possible to complete a placebo-controlled randomized trial of PEP.[25] As the standards for introducing non-validated practices change, so too does the ability of researchers to collect data about safety and efficacy.

This does not mean, however, that research on PEP is precluded.

Alternate study designs with an open arm, or possibly using unequal randomization schemes[26] and comparing different antiretroviral drug regimens, may be an option, so that research can proceed without interfering with the basic prophylactic objectives.[27]

Viewing PEP for possible exposure to HIV as a non-validated practice requiring further research means that discussions about PEP are not straightforward. While there are well-established legal and ethical frameworks for "practice" (that is, diagnosis, preventive treatment, and therapy) and "research," generally there is no analogous well-established framework for "non-validated practice," and so, in considering each of the issues addressed in this paper, one must ultimately determine whether PEP for potential exposures to HIV should be treated more like standard practice or research, and then apply the corresponding framework. To assist those responsible for making such determinations, background information on the legal and ethical aspects of funding, access, informed choice, confidentiality, and liability for PEP is provided within both a research and practice framework. Policy-makers and health-care providers will then be in a position to make separate determinations, for each of these issues, as to whether PEP should be treated as a research or therapeutic manoeuvre.

[Note: the section of the article on funding, focusing on direct drug costs, is not reprinted here]

Access

While funding and access are often considered together, they are separate topics. For the purposes of the discussion that follows, it is assumed that funding for PEP is available, either from government, a pharmaceutical company, private insurance, or the individual. The question then is, "if an individual has possibly been exposed to HIV, should she/he have access to PEP, and if so, on what basis?"

One account of the history of PEP for health-care workers tells the poignant story of an employee at the National Institutes of Health who became infected with HIV and subsequently died. In response,

> ... the center decided to augment risk-reduction efforts by offering postexposure chemoprophylaxis ... to any staff members who were occupationally exposed to HIV.... Although some scientific evidence supported this decision, the most compelling reason behind the center's decision to offer chemoprophylaxis was non-scientific.... [to] send a message of worker advocacy and be seen as empowering exposed workers.[28]

Similar non-scientific reasoning presumably influenced decision-makers at research and health-care centres around the world, and soon there developed the common practice of offering PEP to health-care workers who might have been exposed to HIV. Because PEP was available to health-care workers, the limited data that emerged regarding the safety and efficacy of PEP applied narrowly to this population, and this helped to entrench the practice of limiting PEP to health-care workers. Now, with the increasing perception that PEP may benefit persons potentially exposed to HIV, there is reason to critically examine current practice, and specifically to review the criteria and context for access to PEP.[29]

In Canada there is a fundamental commitment to the principle of justice, and in health care an important aspect of this principle is the fair distribution of the potential benefits of treatment and research. As documented by the National Forum on Health: "Equality of access was one of the most important values consistently advocated. Canadians should have equal opportunity to achieve health and well-being and to receive health services according to their needs." A similar commitment can be found in the newly revised Canadian research guidelines which recognize the benefits of participation in research and prohibit the use of discriminatory inclusion criteria: "researchers shall not exclude prospective or actual research subjects on the basis of such attributes as culture, religion, race, mental or physical disability, sexual orientation, ethnicity, sex or age, unless there is a valid reason for doing so."[30]

> The current practice in some jurisdictions of limiting PEP to health-care workers appears to be inconsistent with the ethical principle that access should not be denied to either treatment or research on discriminatory grounds.

While several jurisdictions in Canada, including Alberta, Yukon, and PEI, have policies that facilitate access to PEP for possible exposure to HIV outside the health-care occupational context, this is not uniform-

ly the case across Canada.[31] The current practice in some jurisdictions of limiting PEP to health-care workers appears to be inconsistent with the ethical principle that access should not be denied to either treatment or research on discriminatory grounds. Is this inconsistency ethically defensible?[32] And, from a legal perspective, does the inconsistency amount to discrimination that could be challenged under the *Canadian Charter of Rights and Freedoms*,[33] or human rights legislation?

Access/inclusion criteria

Possible access/inclusion criteria for PEP are many and include: the setting in which the potential exposure occurs; severity of possible exposure; time elapsed between possible exposure to HIV and the start of PEP; and current HIV status of the exposed person and of the source. Each of these is discussed in detail below.

The setting in which potential exposure occurs

Arguments in defence of the status quo suggest that equal access to PEP for potential non-occupational exposures to HIV, particularly sex- and drug-related exposures, may:

- erode established prevention messages and indirectly encourage high-risk behaviours, such as unsafe sexual practices, because of the perceived availability of a "morning after pill";[34] and
- increase the risk of creating a drug-resistant strain of HIV if PEP is unsuccessful.[35]

In response to the first of these points, advocates of expanding PEP to all possible exposures counter that the potential problem of increased unsafe behaviour is highly speculative and unfounded, given how onerous the PEP regimen is. Further, any such risk could be "minimized through individual counselling and carefully worded public health messages."[36] From a more general perspective, it is also argued that denying PEP to persons with potential non-occupational exposures to HIV is unfair and moralistic. For example, there can be inadvertent possible sexual exposure among those committed to safer sexual practices and unwanted possible sexual exposure among those who are victims of assault. Further, there is reason to question the underlying assumption that access to PEP should be denied when physicians or others assign personal responsibility for potential HIV infection. This is inconsistent with current practice in the Canadian health-care context – persons "responsible" for their ski accidents, their liver damage, or their lung cancer are not denied access to research, non-validated practice, or standard practice on the basis of some failure to promote/secure their health and well-being.

As for the concern about creating a drug-resistant HIV, this is not an argument against expanded access to PEP, since the risk (such as it is) applies regardless of whether the potential exposure is occupational or non-occupational. For example, if PEP is unsuccessful because of suboptimal compliance with or failure to complete the prescribed drug regimen, the route of transmission is scarcely relevant. Secondly, the true incidence and significance of creating drug-resistant HIV strains is unknown. Arguably, the risk of inducing and selecting for drug-resistant viral strains with short-term prophylaxis is not very high; some believe, however, that it may be increased when there is repeated exposure to HIV. This may be a more likely occurrence with possible non-occupational exposures to HIV that are the result of certain lifestyle choices.

The severity of potential exposure

Currently, access to PEP is not solely determined by the setting in which possible exposure occurs. Another important factor is the severity of the potential exposure. In recent years there have been efforts to assess the level of risk, and, on this basis, to determine which health-care workers with possible exposure to HIV should have access to PEP. One proposal is that PEP be:

1. *Recommended* for massive exposure (transfusion),
2. *Endorsed* for dramatic exposure (deep intramuscular/intravenous injection),
3. *Available* for probable exposure (mucosal/subcutaneous needle stick), and
4. *Discouraged* for doubtful exposure (low risk fluids).[37]

Another proposed algorithm suggests:

1. When the risk of HIV transmission is high ("highest risk" and "increased risk" of percutaneous exposure to a larger volume of blood and/or blood containing high titer of HIV), *PEP should be recommended*;
2. When the risk is lower but non-negligible (no increased risk of exposure to larger volume of blood or blood with high titer of HIV, or exposure to fluids containing visible blood or other potentially infectious fluids or tissue), *PEP should be offered*; and
3. When it is negligible (exposure to other bodily fluids), *PEP is not justified.*[38]

Most recently, the CDC has developed a decision tree to assist in determining when it is appropriate to proceed with PEP for health-care workers with potential exposure to HIV – the approach suggested is considerably more sophisticated than others previously available. It seeks to identify more clearly situations in which PEP may not be warranted because the potential side effects and toxicity of PEP outweigh the risk of HIV transmission, and distinguishes these situations from those where it is appropriate to:

1. *Consider a basic regimen;*
2. *Recommend a basic regimen, and*
3. *Recommend an expanded regimen*.[39]

Presumably determinations regarding access to PEP for possible non-occupational exposure to HIV would also require an assessment of the severity of the potential exposure. Clearly, not all such exposures will warrant PEP (for example, exposure to urine). As with the approach to access to PEP for health-care workers, all available information on risk of transmission in other contexts would have to be carefully considered in order to determine how to distinguish legitimately between non-occupational exposures where PEP is not warranted and exposures where PEP should either be considered or recommended.[40]

Time elapsed between possible exposure to HIV and the start of PEP

Animal studies suggest that PEP is not efficacious if started later than 24 to 36 hours after exposure to HIV. The time after which there is no benefit from PEP for humans, however, remains undefined.[41] According to some, the general consensus is that PEP should be started within 72 hours after potential exposure.[42] But are there differences for infections that are transmitted sexually rather than percutaneously? Should the time frame for initiating PEP vary depending upon the source, the setting, or the nature of exposure? If PEP cannot be started within the short "window period," should access be denied on this basis? These are important questions if it happens that persons with potential non-occupational exposures to HIV are not likely to present within 72 hours after potential exposure.[43]

Current HIV status of the exposed person and the source

Because the window period for initiating PEP appears to be 72 hours, it is argued that HIV status should not be an access criterion, though consent to HIV testing should be sought – information from the testing may be relevant to the person potentially exposed. If the person does not test positive, that will be a relevant factor to consider in deciding whether to accept the potential long-term consequences of PEP in healthy individuals; if he or she is already HIV positive, then presumably treatment would be more appropriate than prophylaxis.

A question for further debate and study, however, is whether consent to HIV testing should be an access criterion. This issue, though not irrelevant in the occupational setting, is perhaps more acute with certain potential non-occupational exposures, where there may be a greater likelihood of multiple exposures to HIV, and thus a greater likelihood that the person may already be HIV-positive. With the emerging availability of accessible, rapid HIV testing, the legal and ethical implications of this issue cannot be ignored.

Legal aspects

Current practice is that access to PEP is largely (though not exclusively) determined by the setting in which the potential exposure occurred. The key legal issue therefore is whether a person who is denied access to PEP solely because the potential exposure was non-occupational could use the *Canadian Charter of Rights and Freedoms* or human rights legislation to challenge the denial of PEP as unjustifiable discrimination or infringement of the security of the person.

Discrimination: The Canadian Charter of Rights and Freedoms

For the Charter to be applicable at all, the denial of access would have to be based on a government policy, rather than simply on the decision of an individual physician, since the Charter has been held to apply to government, but not private activity.[44] Then, in order to prove a violation of s 15(1) of the Charter, it would have to be shown that the denial was based on one of the grounds listed in that section (race, national or ethnic origin, colour, religion, sex, age, or mental or physical disability) or on a ground that the court would consider "analogous" (for instance, sexual orientation, although not listed in s 15(1), has been accepted as an analogous ground).[45] It would be difficult to argue that a distinction between those potentially exposed in the workplace and all others potentially exposed to HIV is in itself a violation of s 15(1). However, if it could be shown that access was being denied on the basis of assumed HIV status, then this might be characterized as unequal treatment based on disability.[46] Similarly, if it could be

shown that a significant number of those being denied access were, for instance, drug addicts or gay men, then the grounds of disability or sexual orientation might be used. However, not all denials of PEP would necessarily fit within a listed or analogous ground under section 15(1). Furthermore, even if a court held that s 15(1) had been violated, the government would then have the opportunity to try to show, under s 1 of the Charter, that the restriction being challenged was a reasonable limit that could be "demonstrably justified in a free and democratic society."[47]

Discrimination: human rights

This legislation applies to both government and private activity. All human rights statutes in Canada[48] prohibit discrimination in the provision of services customarily available to the public; the argument would therefore be that PEP for possible exposure to HIV is such a service, and that the refusal to provide PEP to a particular individual was based on a ground protected by the relevant human rights act. The *Canadian Human Rights Act*,[49] for instance, prohibits discrimination based on "race, national or ethnic origin, colour, religion, age, sex, sexual orientation, marital status, family status, disability and conviction for which a pardon has been granted." Again, the issue would be whether the grounds on which PEP was denied would fit within one of the listed categories.

Security of the person

Another possibility might be to argue that s 7 of the Charter, which states, "everyone has the right to life, liberty and the security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice," requires the government to ensure access to medical treatments. In the 1997 case *Sanders* v *Ontario (Ministry of Community and Social Services)*,[50] the applicant sought a declaration that the s 7 rights of a psychiatric patient had been infringed by the Crown's refusal to allow her to undergo a particular treatment which had been recommended by three psychiatrists. The court dismissed the application, stating, "Should the courts dictate to the Crown what treatments will be offered in their various facilities? Both philosophically and practically, the Crown's discretion in this regard ought not to be interfered with except in the clearest and most serious cases."[51] In reaching this conclusion, the court was clearly influenced by the fact that the proposed intervention was "controversial" rather than a "generally accepted treatment."[52]

The "gold standard" of a randomized controlled trial may not be an appropriate approach for research on PEP for possible exposure to HIV; however, this does not mean that attempts to gather further data on the safety and efficacy of PEP should be abandoned.

To consider

If PEP is provided in a therapeutic context, there is the danger highlighted earlier of having a non-validated practice move into the realm of practice without validation. To avoid this, PEP would have to be provided in a research context where uncertainty is acknowledged and managed, there being a plan to systematically gather knowledge/evidence about safety and efficacy.

As discussed in the introduction, the "gold standard" of a randomized controlled trial may not be an appropriate approach for research on PEP for possible exposure to HIV; however, this does not mean that attempts to gather further data on the safety and efficacy of PEP should be abandoned. Also, this does not mean that access to PEP on an "off protocol," "expanded access" or "parallel track" basis, for compassionate[53] or other reasons (for example, ineligibility for research participation, completion of enrollment in the protocol), is precluded. In closing:

> The right to medical treatment does not encompass every drug or intervention that a patient [or physician-researcher] considers therapeutically worthwhile, on whatever evidence he or she has found convincing. Until the therapeutic advantage of an innovation has been demonstrated to the satisfaction of the community of expert practitioners, an innovation is no medical treatment, and so is not covered by a patient's right to access to medical treatments. Consistent with the above, however, we may add that to the extent that a patient's desire to receive [and a physician-researcher's desire to provide] an innovation may be satisfied without jeopardizing the conduct of a clinical trial, then, consistent with good clinical judgment, the desire of the patient [physician-researcher] should be allowed to prevail.[54]

Irrespective of whether PEP for potential exposure to HIV is provided in a research or treatment context, ethical principles would dictate that access should not be based on discriminatory distinctions. It is unclear, however, whether legal arguments for expanded access, based on the Charter and human rights legislation, would in all cases be successful.

[Note: the sections of the article on informed choice, confidentiality, and liability, are not reprinted here]

There is room to improve current policies, and in so doing to carefully consider possible differences among various potential exposures to HIV.

Closing Remarks

Although there is limited information regarding the safety and efficacy of PEP for possible exposures to HIV, the fact remains that PEP is currently available in a treatment context, with or without (partial) government funding, mostly to persons with possible health-care occupational exposures to HIV. As maintaining this status quo does not appear to be an option, the question before policy-makers is how to best modify the current approach to PEP.

One approach would be to introduce or amend provincial/ territorial policies to cover PEP for all possible exposures to HIV, striving for as much consistency as possible. This approach is intuitively appealing because it appears to be both simple and fair. The problem with this approach, however, is that it rests on two questionable assumptions: first, that existing policies are ideal, but for the provisions that limit access based on the setting in which a potential exposure occurs; and second, that there should be a uniform approach to all possible exposures to HIV. In our view, there is room to improve current policies, and in so doing to carefully consider possible differences among various potential exposures to HIV. For example, outside the health-care occupational setting, the following factors may be relevant: delayed recognition of possible exposure, lack of information regarding the HIV status of the possible source of exposure, inability to follow the prescribed regimen, and risk of repeated exposures during a period of prophylaxis. These factors may lessen the efficacy of PEP, or perhaps even increase the possibility of harm from PEP, and so must be considered in policy development.

The challenge brought forward by those who have been denied access to PEP provides policy-makers with a unique opportunity to step back and consider anew, in light of currently available data, the following questions:

- How safe and efficacious is PEP for possible exposures to HIV in the health-care occupational setting?
- How safe and efficacious is PEP for possible exposures to HIV in the non-occupational setting?
- What research is necessary in order to develop further knowledge about the benefits and harms of PEP?
- What ethical principles should inform government decision-making in this area?
- What are the Crown's legal responsibilities, in light of human rights legislation, the *Canadian Charter of Rights and Freedoms,* and tort law?
- How should PEP for possible exposure to HIV fit within an overall national strategy of HIV/AIDS prevention and treatment?
- What ethically and legally justifiable criteria should be developed to distinguish between possible exposures where PEP is not warranted and exposures where PEP should either be considered or recommended?
- What ethically and legally justifiable principles should form the basis for decisions regarding the funding of PEP?
- What procedures should be developed to ensure that individuals offered PEP are provided with sufficient information to make an informed choice, and that confidentiality is properly maintained?

- Françoise Baylis & Diana Ginn

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[1] Terminological precision and conceptual clarity are imperative to the goal of sound reasoning. "The correct description of an action is critical for ethical [and legal] evaluation. A kiss may be just a kiss; but, depending upon the context in which bestowed it may also be a mark of affection, the fulfilment of a contract for services, or as in the Godfather saga, the pronouncement of the death penalty." B. Freedman, A. Fuks and C. Weijer, "Demarcating Research and Treatment: A Systematic Approach for the Analysis of the Ethics of Clinical Research," *Clinical Research* 40 (1992): 653-60, p. 653.

[2] D.M. Cardo, et al., "A case-controlled study of HIV seroconversion in health care workers after percutaneous exposure," *New England Journal of Medicine* 337 (1997): 1485-1490. See also, CDC Cooperative Needlestick Surveillance Group, "Case control study of HIV seroconversion in health care workers after percutaneous exposure to HIV infected blood—France, United Kingdom and United States, January 1994 - August 1994," *Morbidity & Mortality Weekly Report* 44 (1995): 929-33.

[3] R.S. Sperling, et al., "Maternal viral load, zidovudine treatment, and the risk of transmission of human immunodeficiency virus type 1 from mother to infant," *New England Journal of Medicine* 335 (1996): 1621-1629; E.M. Connor, et al., "Reduction of maternal-infant transmission of human immunodeficiency virus type 1 with zidovudine treatment," *New England Journal of Medicine* (1994): 1173-1180.

[4] R.J. Black, "Animal studies of prophylaxis," *American Journal of Medicine* 102, Suppl. 5B (1997): 39-44.

[5] The most recent guidelines from the Centers for Disease Control and Prevention (CDC) for PEP recommend a two drug regimen in certain circumstances, namely zidovudine (AZT) and lamivudine (3TC), with the addition of a protease inhibitor (indinavir or nelfinavir) in certain other circumstances, where an increased risk for transmission exists: CDC, "Public Health Service Guidelines for the Management of Health-Care Worker Exposure to HIV and Recommendations for Postexposure Prophylaxis," *Morbidity & Mortality Weekly Report* 47, Suppl. No. RR-7, (May 15, 1998): 1-14, p. 1.

[6] D. Shelton, "Not a 'morning after' pill: But demand spurs look at HIV antiretroviral use," *American Medical News* 40 (11 August 1997): 1 (from the American Medical Association website: <www.ama-assn.org/public/journals/amnews>.

[7] Centres for Disease Control, "Update: provisional Public Health Service recommendations for chemoprophylaxis after occupational exposure to HIV," *Morbidity & Mortality Weekly Report* 45 (1996): 468-472; J.L. Gerberding, "Prophylaxis for occupational exposure to HIV," *Annals of Internal Medicine* 125 (1996): 497-501.

[8] R.J. Levine, *Ethics and Regulation of Clinical Research*, 2d ed. (New Haven: Yale University Press, 1988): 3-4. These definitions are based on those first articulated in: National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research*, DHEW Pub. No (OS) 78-0012 (1978): 1-20, p. 2-4.

[9] F. Baylis, "Assisted Reproductive Technologies: Informed Choice," in *New Reproductive Technologies: Ethical Aspects*, vol. 1 of the research studies of the Royal Commission on New Reproductive Technologies (Ottawa: Minister of Supply and Services Canada, 1993): 47-107, p. 52-53.

[10] B. Freedman, "Nonvalidated therapies and HIV disease," *Hastings Center Report* 19, no. 3 (1989): 14-20, p. 14.

[11] "Some of the treatments used in everyday clinical practice, and that have acquired the reputation of being standard and established therapies, have never been subjected to the methodological evaluation given to treatments in a controlled clinical trial. The reputation of being a standard or established therapy is often based on little more than clinical rumor, anecdotal evidence, or fashion. In the past, a number of such "standard" treatments [...] had to be abandoned because they were eventually shown, under careful study, to have been either useless or definitely harmful." D.J. Roy, J.R. Williams and B.M. Dickens, *Bioethics in Canada* (Toronto: Prentice Hall, 1994): 319.

[12] A prospective double-blind placebo-controlled trial of post-exposure prophylaxis among health care workers in the U.S. was discontinued because of limited enrollment and the large numbers needed to assess a reduction in the risk of transmission. See S.W. LaFon, S.N. Lehrman and D.W. Barry, "Prophylactically administered Retrovir in health care workers potentially exposed to the human immunodeficiency virus," *Journal of Infectious Diseases* 158 (Special Notice, 1988): 503. S.W. LaFon, et al., "A double-blind, placebo-controlled study of the safety and efficacy of Retrovir (zidovudine, ZDV) as a chemoprophylactic agent in health care workers exposed to HIV," in American Society for Microbiology, *Program and Abstracts of the 30th Interscience Conference on Antimicrobial Agents and Chemotherapy*, (Washington D.C.: American Society for Microbiology, 1990): 167, abstract no.489.

[13] D. Henderson, "Postexposure treatment of HIV—Taking some risks for safety's sake," *New England Journal of Medicine* 337 (1997): 1542-1543. See also D.N. Fish, "Prophylaxis of HIV Infection Following Occupational Exposure," *Annals of Pharmacotherapy* 27 (1993): 1243-56.

[14] L.E. Burns, J.E. Hodgman, and A.L. Cass, "Fatal Circulatory Collapse In Premature Infants Receiving Chloramphenicol," *New England Journal of Medicine* 261, no. 26 (1959): 1318-1321.

[15] Ibid., 1321.

[16] Ibid.

[17] Ibid.

[18] For example, L.N. Martin, et al., "Effects of initiation of 3'-azido, 3'-deoxythymidine (zidovudine) treatment at different times after infection of rhesus monkeys with simian immunodeficiency virus," *Journal of Infectious Disease* 168 (1993): 825-35.

[19] Centres for Disease Control, "Public Health Service Guidelines," see note 5 above, p. 7.

[20] For a more complete discussion of the limitations of the retrospective case-control study see the Editor's note in CDC Cooperative Needlestick Surveillance Group, "Case Control Study... " note 2 above: 932. *Ascertainment bias* refers to possible bias in the way that subjective information is gathered. As regards the study in question, the times at which some relevant information were collected varied between the two arms of the study. It has been noted that "ascertainment bias may have affected some data, particularly subjective variables such as severity of injury, because information for control-HCWs was obtained prospectively soon after exposure but information for most case-HCWs was obtained after seroconversion," (p. 932).

[21] David Sackett provides a useful table that correlates levels of evidence and grades of recommendation. The higher the level of evidence, the higher the grade of the recommendation. See D. Sackett, "A Science for the Art of Consensus," *Journal of National Cancer Institute* 89, no. 14 (1997): 1003-05, p. 1004.

[22] National Commission, *The Belmont Report*, see note 8 above, p. 3. According to Susan Buchbinder, "several studies are in progress or being planned to clarify the benefits and drawbacks of PEP for people exposed non-occupationally, so that health care providers can make sound recommendations", S. Buchbinder, "Avoiding Infection After HIV Exposure," *Scientific American* 279 (1998): 104-105. The Centers for Disease Control has established a "HIV Postexposure Prophylaxis (PEP) Registry" which, with the consent of patients, will "collect information about the safety, tolerability, and outcome of taking antiviral drugs for postexposure treatment." Identifying information will not be collected. From the <AIDSminingco.com> web site.) It should be noted, however, that this registry is intended only for health care workers with possible occupational exposure to HIV (according to the website) so the registry will not provide direct data on the safety or efficacy of PEP in other contexts.

[23] R. Levine, "Comment on Richard Royall's 'Ethics and Statistics in Randomized Clinical Trials'," *Statistical Science* 6 (1991): 71-74, p. 72.

[24] For Canadian guidelines on placebo-controlled studies, see The Medical Research Council of Canada, The Natural Sciences and Engineering Research Council of Canada, and The Social Sciences and Humanities Research Council of Canada, *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (Ottawa: Public Works and Government Services, 1998): p. 7.4.

[25] J. Gerberding, "Is Antiretroviral Treatment after Percutaneous HIV Exposure Justified?" *Annals of Internal Medicine* 118, no. 12 (1993): 979-80.

[26] "Mathematically rigorous data-dependent designs for studies can, in some cases, provide firm information on the effectiveness of a therapy while exposing fewer patients to suboptimal treatment than a conventional trial would. During a data dependent study, the health of the participants is continually analyzed. The accumulating evidence about the different treatments modifies the odds used to select which therapy the next participant will receive." T Beardsley, "Coping with HIV's Ethical Dilemmas," *Scientific American* 279 (1998): 106-107. [An open arm study design allows subjects and researchers to know what drug is being tested. In an unequal randomization scheme, a large group of subjects is randomized to a drug, and a smaller group receives another drug or placebo – ED].

[27] R.J. Levine, *Ethics and Regulation of Clinical Research*, note 8 above, p. 4.

[28] D.K. Henderson, "Postexposure,"note 13 above, p. 1542.

[29] National Forum on Health, *Canada Health Action: Building on the Legacy*, vol. II (Ottawa: Minister of Public Works and Government Services, 1997): 6.

[30] *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (1998): p. 5.2 Clearly, no one can be guaranteed access to pharmaceutical research in order to gain access to a particular drug, for a variety of reasons; the drug in question may not be the subject of research at that time, or the person may not the meet the inclusion criteria, or researchers may have all the research participants they need at a given time. The point is that if research is being carried out, and a person would be otherwise eligible, he or she should not be denied access on discriminatory grounds.

[31] Federal – Health Canada "An Integrated Protocol to Manage Health Care Workers Exposed to Blood Borne Pathogens"; Manitoba – Manitoba Department of Health, Public Health Branch, "Guidelines for Managing Occupational Exposure to Blood/Body Fluids" / "Counselling Guidelines for Clients with Accidental Exposure to Blood or Body Fluids"; Yukon – Yukon Department of Health, "Blood-borne Exposure Management Protocol" ["this protocol is for all persons living or travelling in the Yukon who are accidentally exposed to blood-borne pathogens"]; Prince Edward Island – Prince Edward Island Department of Health and Social Services "Guidelines for the Management of Persons Exposed to Blood Borne Pathogens in An Occupational Or Community Setting"; Alberta – Alberta Ministry of Health "Health Standards for Non-Occupational Community Post-exposure Follow-up and Prophylaxis of Blood Borne Pathogens".

The distinction between those possibly exposed in a health care occupational setting, and those possibly exposed in other contexts appears to be the policy in England as well. See "After Sex Cocktail: A Gay man's struggle through the maze of post-exposure prophylaxis", from the website <AIDSminingco.com>.

[32] For a variety of perspectives on whether the use of PEP should be expanded, see E. Zold et al., "Forum on Using Anti-HIV Drugs Soon After Sexual or Drug-Use Exposure" *San Francisco Bay Area Reporter*, 13 February 1997, as it appeared on the website: <http://hivinsite.ucsf.edu>; M.H. Katz and J.L. Gerberding, "Post Exposure Treatment of People Exposed to the Human Immunodeficiency Virus through Sexual Contact or Injection-Drug Use," (Sounding Board) *New England Journal of Medicine* 336, no. 15 (April 10, 1997): 1097-100; D.K. Henderson, "Postexposure," see note 13 above; and C.C.J. Carpenter et al., "Antiretroviral Therapy for HIV Infection in 1996: Recommendations of an International Panel," *Journal of the American Medical Association* 276, no. 2 (1996): 146-54, p. 152.

[33] *Canadian Charter of Rights and Freedoms*, Part I of *Constitution Act*, 1982, being Sch. B of *Canada Act*, *1982*, 1982, c. 11(U.K.).

[34] "Can HIV be stopped within first 72 hours?" *OUTReach* (newspaper), June 1997, San Francisco AIDS Foundation, from their website: <www.sfaf.org>.

[35] For a discussion of issues relating to drug resistant strains of HIV see M. Wainberg and G. Friedland, "Public Health Implications of Antiretroviral Therapy and HIV Drug Resistance," *Journal of the American Medical Association* 279, no. 24 (1998): 1977-83; O.J.Cohen and A.S. Fauci, "Transmission of Multidrug-Resistant Human Immunodeficiency Virus - The Wake-Up Call," *New England Journal of Medicine* 339, no. 5 (30 July 1998): 341-43; and Katz and Gerberding, "Post Exposure," note 32 above. See also note 6 above.

[36] M.H. Katz and J.L. Gerberding, note 32 above, p. 1098.

[37] D. Fish, "Prophylaxis," see note 13 above, p. 1252.

[38] "Provisional Public Health Service recommendations for chemoprophylaxis after occupational exposure to HIV, by type of exposure and source material—1996," (table) in M.E. Chamberland and D.M. Bell, "Human Immunodeficiency Virus Infection", in J.V. Bennett and P.S. Brachman, eds., *Hospital Infections*, 4th ed. (Philadelphia: Lippincott-Raven Publishers, 1998): 665-87, p. 678.

[39] Centers for Disease Control, "Public Health Service Guidelines," see note 5 above, p. 7.

[40] Criteria for offering PEP to the survivors of sexual assault are described by G. Opio, R. Torres and R. Alvalle, "Post-sexual exposure prophylaxis (PSEP) with HAART after sexual assault," (paper delivered at the 12th World AIDS Conference, 28 June-July 3, 1998, Geneva), conference abstract no. 250/33174.

[41] Centres for Disease Control, "Public Health Services Guidelines," see note 5 above, p. 18; Chamberland and Bell, see note 38 above.

[42] Buchbinder, "Avoiding HIV Infection," see note 22 above.

[43] Results from one study suggest that, in consensual sexual relations, persons potentially exposed to HIV are unlikely to present within 72 hours, in part because they are unaware of their partner's HIV infection. This suggests that the value of PEP for potential non-occupational exposure to HIV, if proven effective, may nonetheless be very limited. P. Sudrel, G. Schockmel, C. Fagard et al., "Post HIV exposure prophylaxis: Who may benefit?" (paper delivered at the 12th World AIDS Conference, 28 June-3 July 1998, Geneva), conference abstract no. 33188.

[44] *Canadian Charter of Rights and Freedoms*, s. 32; see also *McKinney et al* v. *University of Guelph*, [1990] 3 S.C.R. 229-449; *Eldridge* v. *British Columbia* (A.-G.), [1997] 3 S.C.R. 624. Note that there it must also be shown that there has been a denial of equality before or under the law, or a denial of the equal protection or benefit of the law. However, given the discussion of this issue in *McKinney*, it seems likely that a government policy would be found to meet the criterion of "law".

[45] *Egan* v. *Canada*, [1995] 2 S.C.R. 513-626.

[46] The argument might go as follows: you think I am HIV positive and until I prove to you I am not, you are refusing me PEP; thus I am being refused PEP because of a perception that I have a certain illness or medical condition. This constitutes a denial on the basis of disability.

[47] *Canadian Charter of Rights and Freedoms*, s. 1.

[48] *Canadian Human Rights Act*, R.S.C. 1985, c. H-6, s.5; *Human Rights, Citizenship and Multiculturalism Act*, R.S.A. 1980, c. H-11.7, s. 3; *Human Rights Code*, R.S.B.C. 1996, c. 210, s. 8; *Human Rights Code*, R.S.M. 1987, c. H175, s. 3; *Human Rights Code*, R.S.N. 1990, c. H-14, s. 6; *Human Rights Act*, R.S.N.B. 1973, c. H-11, s. 5; *Human Rights Act*, R.S.N.S. 1989, c. 214, s. 5(1)(a); *Human Rights Code*, R.S.O. 1990, c. H.19, s. 1; *Human Rights Act*, R.S.P.E.I. 1988, c. H-12, s. 2; *Saskatchewan Human Rights Code*, S.S. 1979, c. S-24.1, s. 12; *Human Rights Act*, S.Y. 1987, c. 3, s. 8(a).

[49] *Canadian Human Rights Act*, R.S.C. 1985, c. H-6.

[50] *Sanders* v. *Ontario (Ministry of Community and Social Services)* (1997) O.J. No. 552-56 (O.C.J. Gen. Div.) (From QL).

[51] Ibid., at para. 7.

[52] Ibid., at para. 8.

[53] For a discussion of compassionate access, see O. Madore and W. Murray, *National Roundtable on Compassionate Access to Experimental Therapies*, (an unpublished report prepared for the House of Commons Sub-committee on HIV/AIDS, 10 January 1996).

[54] B. Freedman, "Nonvalidated Therapies," see note 10 above, p. 18.

ASSISTED SUICIDE AND EUTHANASIA

Providing Assistance in Dying: A Call for Legalization

The Canadian AIDS Society (CAS) has called for the legalization of assisting in a suicide and of voluntary euthanasia in cases involving individuals who are terminally ill and who have requested assistance in dying. The CAS Board of Directors adopted this position in May 1999, following extensive consultations with its 107 member organizations and associates.

The Position Statement

The complete text of the CAS position statement is as follows:

> The Canadian AIDS Society believes in the fundamental principle of self-determination for persons living with HIV, and for all people, including the right to die with dignity.
>
> The Canadian AIDS Society believes that when mentally competent individuals in the terminal phases of a chronic disease or condition requests assistance in dying, they should be legally entitled to such assistance.
>
> The Canadian AIDS Society therefore calls for the legalization of (a) assisting in a suicide and (b) active, voluntary euthanasia involving individuals in the terminal phases of a chronic disease or condition.
>
> The Canadian AIDS Society believes that legalization should be accompanied by appropriate safeguards to prevent abuse.

The statement is contained in a position paper entitled *A Matter of Choice*.[1]

Definitions

The paper defines "assisting in a suicide" as

> an act done to assist an individual to take his or her own life, where the individual has requested assistance and where such assistance is provided to relieve that individual's suffering.

It defines "euthanasia" as

> an act done to relieve an individual's suffering, where the act results in the death of the individual.

The qualifier "active" refers to cases involving the administration of a treatment or act that induces death. The qualifier "voluntary" refers to cases where the individual has requested assistance to end his or her own life.

CAS has not taken any position on non-voluntary euthanasia (involving an act done without the knowledge of the wishes of the individual) or involuntary euthanasia (involving an act done against the wishes of an individual).

The Canadian AIDS Society emphasizes that suicide prevention and ensuring support for people to live with HIV/AIDS continue to be priorities.

Ensuring Support for People with HIV/AIDS

While CAS calls for the legalization of assisting in a suicide and of active, voluntary euthanasia, it emphasizes

that suicide prevention and ensuring support for people to live with HIV/AIDS continue to be priorities. According to CAS, support and appropriate counseling must be provided to individuals and their caregivers before any action involving assisting in a suicide or active, voluntary euthanasia is taken.

In its position paper, CAS advances the following three main arguments in support of its position:[2]

The Right to Choose

Legalizing assisting in a suicide and active, voluntary euthanasia would be consistent with the principle of individual autonomy – ie, the right to self-determination and the right to choose. People have the right to make decisions about their own health care and to have their wishes respected in matters involving their own body. It is unfair to force people to continue to live when they no longer wish to do so. They should be allowed to choose to leave the world when they are satisfied there is no quality of life left for them, or when their pain and suffering is too great.

Discrimination

Because suicide is legal in Canada, and because some disabled persons are physically unable to commit suicide, the current prohibitions against assisting in a suicide and active, voluntary euthanasia discriminate against disabled persons and therefore violate the equality provisions of the *Canadian Charter of Rights and Freedoms*.

Premature Deaths

The current prohibitions against assisting in a suicide and active, voluntary euthanasia result in many people committing suicide prematurely – ie, before they are truly ready and willing to die. They do so because they feel they cannot afford to wait until they are physically incapable of taking their own lives, or because they do not want to ask their families, friends, and health-care workers to commit an illegal act.

A Call for Guidelines

CAS says that guidelines are required to spell out the process for requesting and carrying out assisting in a suicide and active, voluntary euthanasia in order to prevent abuse, even though this might be seen as infringing upon individual autonomy to some degree. The position paper sets out a number of principles that CAS feels should be embodied in the guidelines.

The position paper also includes a summary of the current state of the law in Canada in this area, as well as a discussion of the arguments advanced by people and organizations opposed to the legalization of assisting in a suicide and of active, voluntary euthanasia.

– David Garmaise

David Garmaise is a consultant in Ottawa and a former Executive Director of the Canadian AIDS Society. He can be reached at <dgarmaise@home.com>. Copies of *A Matter of Choice* can be obtained from Claire Checkland, Communications Assistant, Canadian AIDS Society. Tel: 613 230-3580 ext 126; fax: 613 563-4998; email: <clairec@cdnaids.ca>.

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[1] Canadian AIDS Society. Ottawa: The Society, 1999.

[2] These arguments are discussed in more detail in the position paper and in D Garmaise. The case for assisted suicide and euthanasia. *Canadian HIV/AIDS Policy & Law Newsletter* 1997; 3 (2/3): 20-23.

AIDS VACCINES

AIDS Vaccines and the Developing World

Respect for human rights is key to the development and distribution of AIDS vaccines, yet vaccine research on human subjects in developing (and developed) countries raises considerable ethical and human rights concerns. We reproduce a fact sheet produced by the Interagency Coalition on AIDS and Development (ICAD) that summarizes some of the main concerns while emphasizing that there is no conflict between respect for human rights and the speedy development of an effective vaccine. The fact sheet also provides information about other, essential resources on AIDS vaccines.

What Are the Main Concerns?

- An AIDS vaccine for the developing world is many years away, yet the search for a vaccine may reduce research into and funding of other HIV prevention activities at a time when such efforts must be increased.
- The vaccine initiative does not address underlying issues such as poverty and gender imbalance that drive HIV infection, AIDS, and other preventable diseases.
- Respect for human rights is key to the development and distribution of AIDS vaccines, yet vaccine research on human subjects in developing countries raises considerable ethical and human rights concerns.

What Are the Key Issues?

An AIDS vaccine for the developing world is many years away

It is well known that vaccines have been used successfully to fight serious infectious diseases such as smallpox and poliomyelitis. These public health victories have raised hopes for an inexpensive and effective vaccine against HIV infection or AIDS. Yet many scientific, ethical, legal, and economic obstacles remain – for example, research to establish the efficacy of a vaccine could last 15-20 years, or longer. HIV sub-types found in Africa (which has over 70 percent of the global population of people living with HIV/AIDS) can differ from those in Europe and North America. Even when a vaccine suitable for developing countries is found, the inoculation of communities most vulnerable to HIV-infection and AIDS will probably take many years more.

Prevention efforts must continue today

HIV prevention strategies that are already known to be effective today, such as safer-sex education and the reduction of drug-related harm, must be continued and expanded. We must also continue to fight discrimination and social inequality. Research into new technologies, particularly those that can be controlled by women (such as microbicides and the female condom) must not be side-tracked by the promise of an AIDS vaccine. Because the first vaccines may only delay or prevent progression to AIDS (rather than prevent HIV infection), safer-sex programs will remain essential to stop the spread of HIV infection even when a vaccine is available.

Research in developing countries must benefit developing countries

Some ethicists say that it is wrong to conduct vaccine research on people living in poverty unless there is also a credible plan and financial resources to make the successful products of such research (ie, the vaccines) available to those people. They say we should presume the valid consent of people living in poverty cannot be obtained without such a plan (Annas & Grodin, 1998). In this view, vaccine research that does not include a plan and resources for the distribution of the benefits of the research should not be permitted. This is because the prior informed consent of the trial participants is recognized as a basic ethical requirement of medical research.

Others have suggested that informed consent can be obtained without a plan and resources to make the benefits available to the communities in which the trials take place. In this view, vaccine trials may benefit trial participants both directly (by providing personal protection against HIV infection) and indirectly (by reducing the incidence of HIV in the community at some future time). The benefits of research should be made reasonably available to counter any charge of exploitation. However, the availability of a vaccine to poor communities that participated in the research may be justifiably limited by factors such as price, difficulties of manufacture and distribution, and the infrastructure required for delivery (Harris, 1998).

Human Rights and Ethical Concerns about Vaccine Research in Developing Countries

- Vaccine research on impoverished populations may conflict with current ethical guidelines, such as the requirement for individual informed consent without undue inducement.
- Market-driven vaccine research may focus on HIV sub-types prevalent in wealthier countries, leaving aside those developing countries that cannot afford expensive remedies.
- Vaccine trial participants may take more risks because they think they are protected, even though they may be part of the placebo group, or the test vaccine may be ineffective.
- Inoculation with an early test vaccine may render the trial participant unable to benefit from more effective vaccines developed later on.
- Participants may face societal discrimination if they test HIV-antibody positive as a result of the vaccine (even though they cannot transmit HIV infection), or as a result of participating in the trial.
- There is a tension between the ethical requirement for HIV prevention and education of the trial participants, and the need to maintain some degree of risk behaviour to ensure meaningful results.
- There is disagreement about the standard of medical care that should be offered to trial participants who become infected with HIV during the trial. Some ethicists argue that the standard of care for all participants worldwide should be the best proven treatment (to date, ARVs – combination antiretroviral drugs). In this view, any compromise of this standard, even to reflect local conditions where ARVs cannot practically be provided, is unacceptable. Others maintain that the best local treatment standards are all that is ethically required, and that international research guidelines should be revised to reflect this. A related difficulty is that treatment with ARVs makes it difficult to ascertain whether the test vaccine is effective in reducing progression to AIDS.
- Plans are not yet in place to ensure that a suitable vaccine, once developed, can be purchased, distributed, and administered widely in the developing world.

Conclusion

Respect for human rights is key to the development and distribution of HIV vaccines. There is no conflict between respect for human rights and the speedy development of an effective vaccine:

> It is possible to underplay the human rights concerns that accompany HIV vaccine research and argue that, with 16,000 new infections each day in the world, social issues must not be allowed to slow research and testing. But this perspective gets it backwards. Until participants and communities can be assured fair treatment and the fruits of research in which they are participating, there is little reason to expect that they can be willingly recruited and retained for trials. HIV vaccine research may require a series of large-scale human trials over years or decades. In order to launch ethical trials that sustain the support and interest of the affected communities, ongoing attention to human rights will be critical (Collins, 1998).

Vaccine research in developing countries must be based upon partnerships between developed and developing countries, so that developing countries have a strong voice in deliberating issues such as the availability of a successful vaccine, and the many other ethical issues.

Further Information

T Kerns. *Ethical Issues in HIV Vaccine Trials*. New York: St Martin's Press; London: Macmillan Press, 1997. A clear presentation of the scientific and ethical obstacles to HIV vaccine development.

G Grady. *The Search for an AIDS Vaccine: Ethical Issues in the Development and Testing of a Preventive HIV Vaccine*. Bloomington: Indiana University Press, 1995. Provides an

historical overview from a US perspective, and explores community consultation and decision-making around difficult ethical issues.

World Health Organization. *Globalization and Access to Drugs: Perspectives on the WTO/TRIPS Agreement, Health Economics and Drugs, DAP Series* No. 7 (2d ed). WHO, 1999. An overview of the limitations on pharmaceutical patents provided by the Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS). Under TRIPS, national law may provide for the granting of a compulsory licence for essential new pharmaceutical products, such as a vaccine against AIDS. Contact: Documentation Centre, Essential Drugs and Other Medicines, World Health Organization, 1211 Geneva 27, Switzerland. Email: <darec@who.ch>.

C Collins. HIV Vaccines and Human Rights. In: B Snow (ed). *HIV Vaccine Handbook: Community Perspectives on Participating in Research, Advocacy and Progress.* AIDS Vaccine Advocacy Coalition, 1999 (see web reference below).

G Annas, M Grodin. Human rights and maternal–fetal HIV transmission prevention trials in Africa. In: J Mann et al (eds). *Health and Human Rights.* Routledge Press, 1999. The authors present the ethical arguments for ensuring that the subjects of research in developing countries will benefit from that research.

W Heyward, S Osmanov, J Esparza. Preparing for HIV vaccine trials in developing countries. In: J Mann, D Tarantola (eds). *AIDS in the World II.* New York: Oxford University Press, 1996. A concise discussion on the rationale and approaches for the conduct of scientifically and ethically appropriate HIV vaccine trials in developing countries.

Guidance document on ethical considerations in international trials of HIV preventive vaccines. UNAIDS*

R Lie. Ethical issues in clinical trial collaborations with developing countries – with special reference to preventive HIV vaccine trials with secondary endpoints. UNAIDS working paper, 1998.*

J Harris. Ethical implications of Phase III clinical trials of HIV vaccines. Justice issues: burdens, benefits and availability. UNAIDS working paper, 1998.*

(These documents will be available on the UNAIDS web site in late 1999.)*

Key Organizations and Websites

AIDS Clinical Trials Information Service <http://www.actis.org/actis.asp?URL=vaccine&VIEW=general> contains the AIDStrials database <http://www.actis.org/actis.asp?URL=aidstrial&VIEW=technical>

AIDS Vaccine Advocacy Coalition <http://www.avac.org/>

Consumer Project on Technology: Health Care and Intellectual Property <http://www.cptech.org/ip/health/>

Insite – Gateway to AIDS Information: Vaccines <http://hivinsite.ucsf.edu/topics/vaccines/> contains a useful glossary: <http://hivinsite.ucsf.edu/topics/vaccines/2098.2488.html>

International AIDS Vaccine Initiative <http://www.iavi.org/>

National Institute of Allergy and Infectious Diseases (NIAID) <http://www.niaid.nih.gov/daids/vaccine/default.htm>

UNAIDS <http://www.unaids.org/> contains a list of key materials on vaccines: <http://www.unaids.org/highband/bpc/keymaterials/vaccine/index.htm>

Selected Documents on the Web

Vaccine Vexations: The have-nots are getting less than they bargained for (1999), at <http://www.thebody.com/poz/columns/1_99/gilden.html>. Dave Gilden discusses two of the ethical dilemmas noted above and the limitations of a vaccine for developing nations.

HIV Vaccines and Human Rights (1998), at <http://www.avac.org/readings/handbook/>. Chris Collins argues that respect for human rights is key to the development and distribution of HIV vaccines.

Dying for a Vaccine (1998), at <http://www.thebody.com/poz/survival/7_98/vaccine.html>. Patricia Kahn provides an overview of scientific, political, and financial challenges identified by US and international researchers.

Nine Years and Counting: Will We Have an HIV Vaccine by 2007? (1998), at <http://www.thebody.com/avac/9years/9years.html>. The AIDS Vaccine Advocacy Coalition provides a comprehensive agenda for action.

Paralysis in AIDS Vaccine Development Violates Ethical Principles and Human Rights (1998), at <http://hivinsite.ucsf.edu/topics/vaccines/2098.3940.html>. Jonathan Mann argued that the failure to proceed to field trials is unethical and violates human rights. The failure to act, like silence, has moral consequences.

CRIMINAL JUSTICE

After *Cuerrier*: Legal Network Paper on Supreme Court Decision Released

The Legal Network has released its paper *After* Cuerrier: *Canadian Criminal Law and the Non-Disclosure of HIV-Positive Status.*[1] The Paper analyzes the significance of the Supreme Court's recent decision in the *Cuerrier* case, and makes a number of recommendations to prosecutors, the judiciary, public health authorities, people with HIV/AIDS, and community-based organizations providing services to people with HIV/AIDS. In conjunction with the Paper, the Network has also released its expanded series of eight info sheets on criminal law and HIV/AIDS, which have been updated since their first release and include information about the *Cuerrier* case.[2]

Background

As reported previously in the *Newsletter*,[3] in September 1998 the Supreme Court of Canada released its judgment in *R* v *Cuerrier*,[4] the first case to reach the highest court that dealt with a criminal prosecution of an HIV-positive person for engaging in sexual activity without disclosing their serostatus. Overruling lower-court decisions, the Supreme Court ruled that where sexual activity poses a "significant risk of serious bodily harm," there is a duty on the HIV-positive person to disclose their status. Where this duty exists, not disclosing may constitute "fraud" that renders a sexual partner's consent to that activity legally invalid, thereby making the otherwise consensual sex an "assault" under Canadian criminal law.

Concerns have been raised (including before the Court in *Cuerrier*) about imposing criminal sanctions on those who do not disclose their HIV-positive status and engage in risky activity. In particular, there is concern that, among other detrimental effects, such a policy will deter people (particularly people at higher risk) from getting tested, as well as impede education and undermine counseling efforts to assist with changing behaviour to reduce the risk of transmission. The Supreme Court acknowledged that education and interventions by public health authorities are available to respond to such conduct, but ruled that the criminal law has a deterrent role to play when public health efforts are unsuccessful.

The Legal Network undertook to prepare a detailed analysis of the decision in order to minimize its potential negative consequences on people with HIV/AIDS, on HIV prevention efforts in Canada, and on the provision of care, treatment, and support to people with HIV/AIDS.

The Goals of the Paper

In light of the questions and concerns about *Cuerrier*, the Legal Network undertook to prepare a detailed analysis of the decision in order to:

- assist people with HIV/AIDS, AIDS service organizations and other community-based organizations, health-care workers, lawyers and legal workers, public health

officials, and others in understanding what the decision does and does not mean, and what it may and could mean in a number of contexts; and
- to provide recommendations to policy- and decision-makers such as government and public health officials, prosecutors, police, legislators, and the judiciary as to how *Cuerrier* should – and should not – be interpreted and applied, so as to minimize the potential negative consequences of the decision on people with HIV/AIDS, on HIV prevention efforts in Canada, and on the provision of care, treatment, and support to people with HIV/AIDS.

The Content of the Paper

The Paper provides an overview of the *Cuerrier* decision. Based on the judgment, the Paper then attempts to provide some answers (where possible) as to when an HIV-positive person may risk criminal prosecution if they do not disclose their status, looking at the possibility of HIV transmission through sexual activity, transmission through sharing drug injection equipment, mother–infant transmission, and transmission through invasive medical procedures. The Paper analyzes whether *Cuerrier* does or should apply in these different contexts. Where the conclusion is that *Cuerrier* is applicable, the Paper also considers how the decision applies, as well as indicating how it should not be applied.

In subsequent sections, the Paper also addresses related questions such as the implications of the *Cuerrier* decision for practice by public health authorities and workers, and questions about confidentiality faced by community-based organizations (and others) that learn information about a person's HIV-positive status and/or risky conduct.

People with HIV/AIDS face uncertainty about the obligations imposed by the law.

Disclosure by People with HIV/AIDS

Sexual Activity

The Supreme Court ruled that disclosure of HIV-positive status is required by the criminal law before one engages in sexual activity that poses a "significant risk" of transmitting HIV. As a result of the Court's decision, it is clear that unprotected vaginal or anal intercourse poses a "significant" risk for the purpose of the criminal law.

However, the Court also suggests that "careful use of a condom" may lower the risk sufficiently that it is no longer "significant" and therefore disclosure would not be required. While this remains unsettled in the law, people with HIV/AIDS face uncertainty about the obligations imposed by the law, upon pain of criminal prosecution. The Paper recommends that this defence of practising "safer sex" be expressly recognized by courts in subsequent cases, so as to provide a more manageable alternative to disclosure that still significantly reduces the risk of HIV transmission and protects the HIV-positive person from criminal prosecution. Criminalizing even the HIV-positive person who takes precautions to protect a sexual partner would remove any incentive to practice safer sex, and would be in direct contradiction to the crucial public health message to take such precautions.

The Paper also urges that the justice system take a contextual approach to assessing the "dishonesty" of not disclosing HIV-positive status, so as to acknowledge that disclosure is not always easily made, and in some circumstances may carry serious risk of physical or other kinds of violence. However, no firm legal conclusion can be drawn as to whether the law will develop in this way.

Sharing Drug Injection Equipment

While the *Cuerrier* case dealt with non-disclosure of HIV-positive status before engaging in unprotected sex, the Paper concludes that the principles set out in *Cuerrier* likely directly apply to the situation where someone, using injection equipment they know to have been previously used by an HIV-positive person (such as themselves), directly injects another person without informing them of this fact. (Other criminal charges might be laid where an HIV-positive person does not directly inject their partner, but knowingly lets another person use their equipment without disclosing their status.)

The Paper notes that it is unclear whether, like using a condom for sex, simply cleaning injection equipment on its own will be considered as sufficiently lowering the risk below the level of "significant," so that disclosing HIV-positive status is not required before injecting a drug-use partner with the same "works." The Paper also acknowledges that it is unclear whether simply disclosing HIV-positive status, before injecting a drug-use partner with the same

equipment, would be sufficient to ensure that their consent to being injected is legally valid. Courts could, for public policy reasons, refuse to accept that a person can consent to being injected with uncleaned equipment containing blood from an HIV-positive person, even if they were aware of their partner's status.

While these questions remain unsettled in the law, the Paper recommends that, at a minimum, there should be no criminal liability on the person who both discloses their status and cleans their equipment before another person is injected with it. The Paper also suggests that a contextual approach again be adopted, to acknowledge that in some circumstances (eg, in prisons) an HIV-positive drug user not only may face serious consequences upon disclosing their status, but also has no access to sterile injection equipment and is therefore forced to rely upon cleaning equipment. As this is consistent with standard public health advice that equipment should at least be cleaned when no safer option (eg, avoiding sharing) is available, it would be counterproductive to criminally punish the HIV-positive inmate who makes this effort at preventing transmission.

Cuerrier provides no basis for criminal liability for HIV transmission from mother to child during pregnancy or delivery.

Mother–Infant Transmission

Cuerrier provides no basis for criminal liability for HIV transmission from mother to child during pregnancy or delivery. However, because of the uncertainty regarding the degree of risk of transmitting HIV through breast-feeding, a broad interpretation of the *Cuerrier* decision might lead to the conclusion that an HIV-positive mother who breast-feeds her infant could be prosecuted for assault for exposing the child to a "significant" risk of infection. Given the epidemiological and legal uncertainty of this question, the Paper recommends that HIV-positive mothers need to be counseled to refrain from breast-feeding, and that governments and responsible parties need to ensure that HIV-positive mothers have the information and necessary supports (including financial assistance) to ensure access to breast-milk substitutes.

Transmission via Invasive Medical Procedures

Given that many medical procedures involve physical contact between patient and health-care worker, applying the *Cuerrier* decision in a health-care context means that a criminal charge of assault could likely be sustained where an HIV-positive health-care worker does not disclose their status to a patient before engaging in a procedure carrying a "significant" risk of transmission, because the patient's consent to that procedure could be said to be vitiated (rendered legally invalid) by the non-disclosure. Similarly, an HIV-positive patient could be subject to the same duty to disclose where the procedure posed a "significant" risk of transmission to the health-care worker.

However, the Paper concludes that the use of universal precautions should more than suffice in almost all circumstances to sufficiently reduce any risk of HIV transmission. In such cases, there should be no "significant" risk, and the Paper recommends that there should therefore be no duty (under the criminal law) to disclose HIV-positive status.

Cuerrier does not change existing legal obligations in the field of public health practice. The basic principles governing pre- and post-test counseling and partner notification remain the same.

The Paper concludes that it is only in the case of "exposure-prone procedures," which by definition carry a "significant risk" of transmission, that there may be a duty to disclose. The Paper does not take up the debate over which procedures should be considered to fall into this category, but concludes that *Cuerrier* may impose criminal liability on the HIV-positive person (health-care worker or patient) who does not disclose their status before such a procedure. However, the Paper offers a reasoned prediction that HIV-positive health-care workers who follow existing, established professional guidelines regarding universal precautions, and expert advice regarding "exposure-prone procedures," likely need not worry about possible criminal prosecution, as they will not have engaged in activities that are considered to pose a "significant" risk of transmission. As this is not clearly established in the law, the Paper recommends this position to prosecutors and the judiciary, should they be called upon in future to consider the application of *Cuerrier* to the medical context.

The Paper also concludes that *Cuerrier* does not require professional bodies to revise their policies or guidelines with a view to making them more restrictive of practice by HIV-positive health-care workers.

Cuerrier and Public Health Law, Policy, and Practice

The *Cuerrier* case only speaks to the question of whether and when an HIV-positive person has a duty to disclose their status because of a risk to others. However, questions have also been raised about what the decision means for public health authorities.

The Paper confirms that *Cuerrier* does not change existing legal obligations in the field of public health practice. The basic principles governing pre- and post-test counseling and partner notification remain the same. However, the Paper recommends that counseling must incorporate accurate information about the *Cuerrier* decision and the possibility of criminal charges for engaging in activity posing a "significant" risk of transmission without disclosing.

Cuerrier highlights the importance of ensuring that public health interventions continue to be conducted on the principle of a graduated response (ie, "least intrusive, most effective" measures to be tried first), that such measures be fully explored before resort is had to the criminal law, and that there be adequate procedural safeguards in place against the misuse of coercive public health measures. The Paper recommends that prosecutors consult with public health authorities before laying or pursuing criminal charges to determine whether measures under public health legislation offer an alternative to prosecution.

Disclosure of Confidential Information Compelled by Law

The *Cuerrier* case has also raised questions (albeit not for the first time) about the confidentiality of information about a person's HIV-positive status and/or conduct that risks transmitting the virus.

The Paper confirms that the *Cuerrier* decision does not affect the obligation to report HIV/AIDS diagnoses under applicable public health law.

Nor does it alter or expand any common law "duty to warn" someone known to be at risk of HIV infection as a result of information gained through a confidential relationship. The Paper notes that it is unclear in Canadian law whether a community-based organization (or, for example, a counselor working in such an organization) would be found liable for negligence if they did not breach the confidentiality of their relationship with an HIV-positive person in order to warn a sex or needle-sharing partner to whom they had not disclosed their status. However, organizations may wish to consider obtaining legal advice and drafting policy to guide counselors or others who may face this difficult question.

The Paper also notes that disclosure of confidential information about a person's HIV-positive status and/or conduct that risks transmission to others may be compelled by search warrant or subpoena for use in a criminal prosecution. Information held by a community-based organization serving people with HIV/AIDS may be sought for such purposes. The Paper therefore recommends that community-based organizations ensure that those to whom they provide support services (eg, counseling) be made aware of this possibility before revealing information that may constitute evidence of criminal activity. The Paper also recommends that organizations, with the assistance of legal advice, consider developing some policies (especially for counseling staff and volunteers) for dealing with confidential information about a person's HIV status or risk activities, and the disclosure of that information. Such a policy could include a protocol for responding to prosecutors requesting confidential information or police executing a search warrant.

– Richard Elliott

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Copies of *After* Cuerrier*: Canadian Criminal Law and the Non-Disclosure of HIV-Positive Status*, and of the eight info sheets on criminal law and HIV/AIDS, can be retrieved from the website of the Canadian HIV/AIDS Legal Network at <www.aidslaw.ca> or ordered through the Canadian HIV/AIDS Clearinghouse (tel: 613 725-3434; fax: 613 725-9826; email: aids/sida@cpha.ca).

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[1] R. Elliott. *After* Cuerrier*: Canadian Criminal Law and the Non-Disclosure of HIV-Positive Status.* Montréal: Canadian HIV/AIDS Legal Network, 1999.

[2] Criminal Law and HIV/AIDS Info Sheets 1-8: Montréal: Canadian HIV/AIDS Legal Network, 1999.

[3] R. Elliott. Supreme Court rules in *R* v *Cuerrier*. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(2/3): 1, 17-24.

[4] (1998), 127 CCC (3d) 1.

Criminal Law and HIV/AIDS: Update I

Since the last issue of the *Newsletter,* there have been developments in several jurisdictions in the area of criminal law and HIV/AIDS. This article reviews recent developments in the case of *R* v *Cuerrier*. It also reviews developments in the United Kingdom, New Zealand, Namibia, Trinidad and Tobago, and the United States.

Canada

As reported in the spring 1999 issue of the *Newsletter*, in September 1998 the Supreme Court of Canada released its decision in *R* v *Cuerrier*.[1] The Court ruled that a person may legally be charged with the offence of *assault* if they do not disclose their status to a partner before engaging in conduct that poses a "significant risk" of transmitting HIV or another sexually transmitted disease that causes "serious bodily harm."[2] Ruling on the legal question before it (and not the actual merits of the case), the Supreme Court decided that the accused could be tried on the original two charges of aggravated assault and ordered a new trial.

In a media statement released on 28 May 1999, the British Columbia Attorney General announced that it would not be proceeding with a new trial against Cuerrier:

> Given the unique circumstances of this case, including the reluctance of the complainants to go through another trial, the fact they have not contracted HIV, the amount of time Mr. Cuerrier has already spent in custody on these charges, and the fact he appears to no longer be a public risk as he has stabilized his personal life, the Crown has decided not to re-try the case against him.[3]

This decision by the BC Attorney General does not alter the significance of the *Cuerrier* decision by the Supreme Court. That ruling determining that the offence of assault may be applicable to the non-disclosure of HIV-positive status stands, and can be expected to guide the development of the criminal law relating to HIV transmission/exposure in future cases.

United Kingdom

In January 1999 the Court of Appeal for England and Wales considered an appeal from sentence by a schizophrenic man who pleaded guilty to a number of charges originally arising out of a domestic dispute. The accused struggled with police upon being arrested (for damage to property and assaulting a repair worker), leading to bleeding injuries on his arms and face. Having earlier informed police that he was HIV-positive, he later spat in an officer's face. She wiped her eye with her sleeve before realizing it was covered in his blood. On this basis, he was charged with *assault occasioning actual bodily harm*, which the Court stated "arose from the inevitable distress that the woman police officer suffered at a time when she and others understood that the appellant was HIV positive." Soon afterward, the accused apologized to the officer and informed her that he did not "have AIDS." He also offered a blood sample, which yielded an HIV-negative diagnosis. Upon pleading guilty, he was sentenced to two-and-a-half years' imprisonment on this charge, to be served consecutively after sentences for the other charges. The appellate court lowered this to 18 months, to run concurrently with the other sentences.

New Zealand

In early May 1999 it was reported that New Zealand police had arrested a man for allegedly having sex with other men without disclosing his HIV-positive status. According to police, the man's sexual encounters took place in a park and other cruising locations. It was reported that police have also identified a second man to be charged for similar conduct, but he was not yet in custody.[4]

Namibia

The PanAfrican News Agency reported in May 1999 that the trial continues in the Namibian High Court in the case of an HIV-positive man charged for allegedly raping a 10-year-old girl, who was infected with the virus.

Trinidad and Tobago

In early May 1999, InterPress Service reported on the death from AIDS-related complications of Dennis Franklyn Williams, a well-known calypso composer. His ex-wife alleged that his female partner, from whom he allegedly contracted HIV, knew she was HIV-positive, and called for her to be "quarantined." In response, a legal research officer from the country's Law Commission indicated that the Commission has already considered the issue of criminalizing HIV exposure, and has recommended against such a move because of concerns that it could be counterproductive to send out the "wrong message" that the law can protect against HIV. Instead, the Commission recommended intensified efforts at education, voluntary testing, and counseling. However, a government discussion paper has recommended that those charged with sexual offences be subject to mandatory HIV

testing and that compensation be paid to victims of sex offences whose assailants test HIV-positive.[5] The paper also recommends a comprehensive HIV/AIDS education program, particularly in secondary schools.

United States

In May 1999 the US Supreme Court delivered a unanimous ruling in the case of an HIV-positive Air Force officer court-martialed and imprisoned for having unprotected sex. The major was ordered by a superior officer to disclose his status to his sexual partners and to use methods (including condoms) to prevent transmission. He was convicted in 1994 of wilfully disobeying this order from a superior officer, aggravated assault with means likely to produce death or grievous bodily harm, and assault consummated by battery, in violation of the Uniform Code of Military Justice, for having unprotected sex with two women. His sentence of six years' imprisonment was subsequently shortened. In 1996 the US Congress enacted legislation permitting the President to drop from the Armed Forces' rolls any officer who had been both sentenced by court-martial to more than six months' imprisonment and who had served at least six months. The Air Force subsequently sought to remove the HIV-positive officer from its rolls, which would mean the loss of his health-care coverage along with military pay. The US Court of Appeals for the Armed Forces ruled this dismissal would constitute a second punishment for the same act, in violation of the constitutional protection against "double jeopardy." However, the US Supreme Court ruled unanimously that the military court had no jurisdiction to block such executive action by the President, and set aside the lower court's injunction.[6]

- Richard Elliott

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[1] (1998), 127 CCC (3d) 1 (SCC).

[2] For more detail, see the article, After *Cuerrier*: Legal Network Paper on Supreme Court Decision Released, in this issue of the *Newsletter*. See also R Elliott. *After* Cuerrier*: Canadian Criminal Law and the Non-Disclosure of HIV-Positive Status*. Montréal: Canadian HIV/AIDS Legal Network, 1999; Criminal Law info sheets 1, 7 and 8. Montréal: Canadian HIV/AIDS Legal Network, 1999.

[3] Media Statement: BC Ministry of the Attorney General (Criminal Justice Branch), Victoria, 28 May 1999; No new trial for AIDS carrier. *Globe and Mail*, 29 May 1999, A8.

[4] R Wockner, International News #262, 3 May 1999, archived at: <www.qrd.org/qrd/www/world/wockner.html>.

[5] W Gibbings. Legal Minds Say No to More Laws on AIDS. Inter Press Service, 13 May 1999.

[6] *Clinton* v *Goldsmith*, United States Supreme Court, Decision No 98-347, 17 May 1999, rev'g 48 MJ 84, downloaded from Supreme Court Collection of the Legal Information Institute, at <http://supct.law.cornell.edu/supct/html/98-347.ZO.html>; R Carelli. Court: President can fire military. Washington: Associated Press, 1999, <www.ap.org>, downloaded from <www.aegis.com/news/ap/1999/AP990507.html>; US top court upholds military officer's discharge. Reuters, 17 May 1999.

US Sentencing Cases

In two recent cases, US courts had to decide about whether criminal defendants who are HIV-positive but do not have AIDS are entitled to a downward departure under sentencing guidelines.

Downward Departure Made Despite Lack of AIDS Diagnosis

In the first case, a New York man convicted of conspiring to traffic in cocaine was freed from federal prison after 13 months in detention because his advanced HIV disease warranted a downward departure in sentencing.[1]

Under federal guidelines, a judge has the authority to reduce a defendant's sentence below the usual range if there is evidence of an "extraordinary physical impairment." The US Sentencing Commission does not spell out which impairments qualify. Courts have reached differing conclusions about how severe the condition must be to qualify for leniency. With HIV, the trend has been that infection alone does not warrant a downward departure, but advanced symptoms of the disease might. The cases are fact-specific. In one instance, a court turned down a petition because it did not lay out a sound factual foundation about the defendant's health.

In this case, the ruling was based not only on the defendant's current symptoms, but also his susceptibility to opportunistic infections in prison and the prospect of increasingly serious health problems in the future.

No Downward Departure for Defendant with HIV

In another case, *US* v *Smith*,[2] the US Court of Appeals for the 7th Circuit held that criminal defendants who are HIV-positive but do not have "full-blown" AIDS are not entitled to a downward departure under the federal sentencing guidelines.

The court commented: "Because Smith concedes that while HIV positive he does not have 'full-blown AIDS,' and because the record suggests that the Bureau of Prisons is equipped to adequately treat Smith's condition, any argument that the district court abused its discretion in denying a downward departure would be frivolous."

[1] *US* v *Hammond*; ED NY, No CR 98-51 (JBW). Decided 18 February 1999. Reported in *AIDS Policy & Law* 1999; 14(6): 2.

[2] 1999 WL 89050; 7th Cir, 19 February 1999 (unpublished decision). Reported in *Lesbian/Gay Law Notes* April 1999, at 61.

BLOOD AND BLOOD SAFETY

France: Criminal Prosecution Collapsed

A criminal prosecution against former French government officials for allowing HIV-tainted blood to be used for transfusions at a time when screening tests were available essentially collapsed.

Former Prime Minister Laurent Fabius, now speaker of the lower house of the French Parliament, and Georgina Dufoix, who had served as Social Affairs Minister in the Fabius government from 1984 to 1986, were acquitted of criminal and civil liability by a specially constituted political jury. Edmond Herve, who had served as Health Minister, was convicted of two counts of negligence, but no sentence was imposed.[1]

Public outcry over the conduct of the trial rivaled, and in some cases eclipsed, responses to the verdicts. The specially constituted Republican Court of Justice, made up of three judges and 12 Members of Parliament, was widely criticized for the verdicts. A constitutional expert, Mr Olivier Duhamel, said the trial had shown it was impossible to reach fair decisions "with a court made up of MPs disguised as judges."[2]

[1] New York Times, 10 March 1999.

[2] Quoted from the [Australian] *HIV/AIDS Legal Link* 1999; 10(1): 24, with reference to *The Age* (Melbourne), 11 March 1999.

Iranian Blood Transfusion Organization Charged with Criminal Negligence

Reuters news service reported in early June 1999 that court proceedings were to start shortly against the Iranian Blood Transfusion Organization.

The Organization was charged with criminal negligence in screening blood purchased from a French pharmaceutical company in 1994. A spokesperson for Iran's Hemophiliac Association was reported as saying that Iran was advised in 1994 that it needed to improve its testing of blood, and that it would be demanding compensation from the French pharmaceutical company as well. According to the spokesperson, at least 187 people have been infected with HIV in Iran as a result of the contaminated blood.[1]

[1] Iran court proceedings to start in blood scandal. *Reuters*, 8 June 1999.

PUBLIC HEALTH

The Montréal Model: Public Health and People with HIV/AIDS Who Do Not Take Precautions

For dealing with situations in which an HIV-positive person does not take precautions to prevent infecting others, do public health laws offer better alternatives than criminal prosecutions? If so, how should public health interventions be approached? This article presents a model developed by public health in Montréal, where a comité d'aide aux intevenants (the CAI, or Committee) has been in existence since 1996. The Committee helps care providers dealing with HIV-positive people who, without disclosing their serostatus, have sexual relations or use injection drugs without taking precautions to avoid HIV transmission. The article describes how the CAI operates, the services it provides, and the principles that guide its actions.

Introduction

Among those concerned, there seems to be unanimity about the need to have a common approach to how to intervene with seropositive people who, without disclosing their serostatus, have sexual relations or use injection drugs without taking precautions to prevent HIV transmission. It was this consensus that in 1995 led interested parties in the Montréal region to work on the development of an intervention policy on the issue. An ad hoc committee made up of people with HIV, representatives of the communities affected by the disease, clinicians, social workers, a psychiatrist, a bioethicist, lawyers, and public health professionals was therefore set up. The development of the policy was based on a review of the literature on the various approaches being taken around the world and on a series of interviews with representatives of the Montréal communities.

The policy was submitted in June 1996. It recommends, on the one hand, prevention and support actions for people with HIV and, on the other hand, concrete help for care providers so that they can manage difficult cases using a graduated-response approach.[1] The CAI is one of the tools for implementing the policy, and its mandate is to support care providers dealing with these cases.

In 1997 and 1998, a pilot project was undertaken to define how the CAI would operate, and in particular its general principles, approaches, and procedures; the intervention process itself was also evaluated.

Target Population

There are many reasons why some people do not take appropriate precautions and put their partners at risk, such as:

- they are genuinely unaware that their conduct involves risks for other people (eg, they have a mental health problem);
- they cannot change their behaviour due to physical threats or coercion (domestic violence, threats from a pimp, etc);
- they are temporarily unable or temporarily refuse to take precautions because they are going through a period of physical or emotional stress; or
- they understand the dangers of HIV transmission but persist in putting their partners at risk.

With regard to the latter, it should be noted that the concept of risk may vary from group to group. The great majority of cases brought before civil or criminal courts against people who are "unwilling or unable" involve heterosexual sexual relationships. These are also the majority of cases heard by the CAI, despite the fact that gay men are far and away the people most affected by HIV in Québec and in Canada.[2] This may be an indication of significant cultural differences between the heterosexual and homosexual populations with regard to the seropositive person's perception of their responsibility for disclosing their serostatus, and of everyone's responsibility – whether seropositive or not – for protecting themselves from HIV infection.

The CAI's Mission

The CAI is a committee of professionals and other interested parties with expertise and/or life experience that enables them to counsel care providers who are dealing with cases of seropositive people who, without disclosing their serostatus, have sexual relations or use injection drugs without taking precautions to counter HIV transmission. The Committee promotes a graduated-response approach. Those who use the Committee's services do so voluntarily and have no legal obligation to follow its recommendations.

Basic Principles Guiding the CAI's Activities

Graduated-response approach

In the recommendations it makes to care providers, the CAI favours a graduated-response approach. The most effective interventions are generally those that, while they achieve the desired behaviour changes, are the most accessible and the least restrictive from the point of view of individual freedoms. Thus, voluntary measures aimed at behaviour modification are first suggested, such as counseling by specialist resource persons who have been selected beforehand, community support, or buddy support. However, the person must understand from the outset that refusal to cooperate with and follow these voluntary measures will be perceived as a possible indicator that the person will continue to practise unsafe behaviours and that this will eventually lead to more coercive measures (fines, injunction ordering counseling or detention).

Although rare, there are situations in which these more coercive interventions are necessary. However, the dissuasive and punitive objectives attaching to penal sanctions have not proved useful in preventing HIV transmission. In the context that concerns us here, public health laws can be an alternative to criminalization because they are, in general, better adapted to the particular facts of each case. They have the requisite flexibility for personalizing interventions, they respect confidentiality, and they are less likely to stigmatize. Contrary to criminal proceedings, they make it possible to proceed from less coercive to more restrictive measures. We feel that coercive measures imposed from the outset can adversely affect preventive actions in many ways.[3] They can:

- increase stigmatization of all people with HIV, whereas only a minority practise these high-risk behaviours. This is particularly true in the context of the "fight against AIDS," the "war on drugs," and intolerance toward cultural and sexual minorities;
- dissuade people at risk from being tested. These people are thus deprived not only of available treatments, but also of an opportunity to receive any personalized preventive intervention they may be offered when they contact the health service involved for testing. Moreover, attributing a criminal aspect to HIV transmission will not encourage people who cannot or do not wish to practise safer behaviours to discuss their respective risk with their partner, counselor, or doctor, for fear of being prosecuted;
- promote the establishment of a false sense of security among the general public by giving the false message that the criminal law is capable of protecting them. This runs counter to public health messages that suggest to individuals that maintaining or adopting safer behaviours is the best way of protecting oneself and others from HIV infection.

The right to sexual activity of people with HIV/AIDS

Seropositive people too are sexually active and can remain so for years; the principle of the autonomy of these people includes the right to have sexual relations.

Protection

However, where there is knowledge that an individual is behaving in such a way as to endanger the life of another person, it would seem acceptable to limit the principle of autonomy just mentioned. Although responsibility for protecting oneself against HIV transmission is the responsibility of each person, public health authorities must, for ethical and legal reasons, ensure that there are mechanisms for reacting in the most appropriate way in the case of individuals who, without disclosing that they are seropositive, expose others (through sexual relations or unsafe injection practices) to the risk of contracting HIV.

The services provided by the CAI

The CAI is composed of a permanent core of members whose expertise is complementary. It provides support to clinical practitioners and other care providers to resolve these complex situations. Consultations can take place without there being disclosure of the identity, or of information that makes possible the identification, of the person in question. The doctor or other care provider is at all times in charge of monitoring the case. The CAI provides:

- information on the most recent recommendations concerning these difficult situations made by professional corporations and associations;
- the services of a liaison officer working at the Infectious Diseases Unit, to evaluate risk situations and

their ethical, judicial, and legal context; to suggest appropriate referrals; to facilitate rapid access to resources (eg, a psychologist); and to participate in a discussion of a case individually or as part of a team;

- the possibility of discussing difficult cases directly with Committee members at one of its meetings. The care provider's presence at CAI discussions is strongly encouraged, as this makes it possible to determine with the care provider, in a creative way, the type of intervention appropriate to the specific needs of the case. Suggested actions are guided by the principles set out above, considered in the context of the best interest of the individual in question and of public health.

The CAI's Operating Principles

The following principles have been adopted :

1. The Committee members undertake to protect the strictest confidentiality with regard to the cases submitted to it, and the Committee's discussions, recommendations, and decisions. This obligation remains even after their mandate as Committee members terminates.
2. All the Committee's discussions and decisions are aimed at helping care providers in their actions, but does not substitute for them.
3. The Committee does not intervene directly with clients. It clarifies the issues. It debates the values involved in the case submitted and suggests choices or means acceptable and available to the care providers and organizations involved and to society.
4. The proposed interventions should not endanger the safety of the people concerned, or of those around them.
5. Proposed interventions will be weighted and balanced; their scope must be proportional to the desired behaviour change.
6. The Committee's recommendations must promote the use of an effective and reasonable approach while limiting as little as possible the rights and freedoms of the individual concerned.
7. The Committee's recommendations do not have the force of law; they are based on the individual and collective experience of its members.
8. Because the difficulties encountered by care providers may be influenced by the organizational and structural limitations of their environment, the Committee's recommendations are not limited to the care provider, but may also, with the care provider's permission, be addressed to third parties. The CAI may suggest to public health, for instance, interventions with respect to policies and programs that may influence and support the organizations and the players in the relevant areas.
9. The relevant information must be verified (eg, the seropositivity of the person in question). Serious grounds must be established before there can be intervention in the private life of a citizen. Because our experience has shown that accusations are sometimes unfounded, the CAI will not deal with them, but will forward such calls to first-line resources capable of making the necessary verifications.
10. Proposed interventions must be consistent with the other interventions being made in controlling the transmission of HIV infection: primary prevention, reorganization of services, etc. Such interventions in the lives of these people also requires taking into account certain problems in everyday life (eg, domestic violence).

Experience Acquired by the CAI

As of mid-1999, around fifteen cases had been dealt with by the CAI. For the most part, these cases involved a risk of heterosexual transmission. There have also been a greater number of cases of individuals with diminished intellectual capacity.

The quality of the working climate and the high level of discussion achieved after two years in operation are one of the Committee's strengths. The stability of the CAI's membership has been a major factor in the success of its work. Complementary activities involving ongoing professional development concerning ethical, legal, social, and other issues (seminars, subscription to documents and publications of interest, circulation of texts on an ad hoc basis) are being undertaken in a systematic way to refine the working skills of Committee members.

– Alix Adrien

This text was prepared by Alix Adrien and the members of the CAI. Alix Adrien is consultant physician with the Direction de la Santé publique, Montréal-Centre. He can be reached at <aadrien@santepub-mtl.qc.ca>.

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[1] D Thompson, A Adrien, G Lambert, R Jürgens et al. *Réduction de la transmission du VIH par les personnes refusent de prendre les précautions nécessaires ou qui sont inaptes à le faire*. Module de prévention et contrôle des MTS/sida, Unité des maladies infectieuses, Hôpital général de Montréal, November 1995.

[2] Centre québécois de coordination sur le sida. *Surveillance des cas de syndrome d'immunodéficience acquise (sida), Québec. Cas cumulatifs 1979-1998*, Update No 1998-2, Montréal, 31 December 1998.

[3] See Criminal Law and HIV/AIDS Info Sheet #4. Criminalization: Does It Make Sense? Montréal: Canadian HIV/AIDS Legal Network, March 1999.

DISCRIMINATION

HIV/AIDS and Discrimination in South Asian Communities: An Ethnocultural Perspective

South Asians with HIV/AIDS experience stigma within a silent community that denies HIV/AIDS is a reality for South Asians. This is the main finding of a project sponsored by the Alliance for South Asian AIDS Prevention (ASAP), one of the first of its kind in Canada to examine HIV/AIDS in a specific cultural community.

Background

In 1998 the Canadian HIV/AIDS Legal Network and the Canadian AIDS Society's Joint Project on Legal and Ethical Issues issued two reports, *HIV/AIDS and Discrimination: A Discussion Paper*[1] and *Gay and Lesbian Issues and HIV/AIDS: Final Report*,[2] both of which recognized that people with HIV/AIDS who identify with a specific ethnic or cultural community face unique challenges. This project builds on the work already completed and makes an important contribution to the understanding of the barriers and challenges faced by members of the South Asian communities.

Sponsored by ASAP and funded by Health Canada, the project was carried out by an independent consultant team under the guidance of a Project Advisory Committee comprised of South Asian community members, half of whom were HIV-positive. The consultant team conducted in-depth, confidential interviews with 21 South Asians living with or affected by HIV/AIDS, as well as 31 key informants, most of whom were from AIDS service and South Asian organizations in the Toronto area.

Key Findings

The key findings of the project are as follows:

- South Asians have a very strong collective culture that is protective of traditional ideas about male/female roles and sexuality. South Asians perceive themselves as being monogamous, sexually inactive (outside of marriage), and family-oriented. South Asians do not acknowledge gay or bisexual South Asian identities, and view HIV/AIDS as a gay white man's disease. Accordingly, the (mis)perception is that HIV/AIDS does not happen to South Asians.
- The community's silence and denial about HIV/AIDS results in stigma being experienced by South Asians who are HIV-positive. They fear being mistreated, abandoned, or isolated if they tell other South Asians about their status.
- South Asian women face a particularly difficult burden in dealing with HIV/AIDS, since codes of sexual conduct or behaviour are more rigidly applied to them. Women risk being labeled promiscuous and as falling below the high standard expected of caregivers/nurturers in the South Asian family unit.
- Faith is a central part of many South Asians' lives, yet faith communities are often the guardians of the prevailing myths that con-

South Asian women face a particularly difficult burden in dealing with HIV/AIDS, since codes of sexual conduct or behaviour are more rigidly applied to them.

tribute to the silence about HIV/AIDS in the first place. Religion and spirituality are nevertheless important means by which South Asian people with HIV/AIDS become reconciled with their lives.
- There is limited experience within the organized South Asian communities, including South Asian physicians, in dealing with HIV/AIDS issues. This means that South Asians are typically turning to mainstream support services that are not reflective of their linguistic, social, and cultural reality.
- South Asians with HIV/AIDS experience discrimination in the areas of health care, welfare, employment, housing, immigration, travel, business, and the law.

Given the silence about HIV/AIDS within the South Asian communities and the everyday racism encountered by South Asians as members of a marginalized part of Canadian society, it is difficult to know the degree to which individuals experience discrimination related specifically to HIV/AIDS. The larger implication of the findings is that South Asians, already vulnerable to racism and marginalization in Canada, are also at risk for the spread of HIV/AIDS. Denial, ignorance, stigma, and silence are all conditions that can lead people to engage in high-risk behaviour, and education strategies to be rendered ineffective.

Key Recommendations

The project's central recommendation is that a broad, multi-pronged social marketing strategy be developed in South Asian communities to change prevailing ideas and break the silence about HIV/AIDS. The strategy should be publicly funded and guided by a consortium of key South Asian business people, physicians, media, faith leaders, and South Asians with HIV/AIDS. Once piloted in Toronto, the strategy should be implemented nationally in major centres across Canada, taking local realities into account.

The project also recommended that:

- funders require mainstream AIDS service organizations in Toronto to become representative of and responsive to Toronto's diverse ethnic communities;
- ASAP improve its own reflectiveness and representation of people with HIV/AIDS at the governance and staff levels of the organization;
- ethno-specific AIDS service organizations such as ASAP advocate to ensure that people of colour and women are included in HIV/AIDS clinical research initiatives underway in Canada;
- ethno-specific AIDS service organizations such as ASAP advocate for changes to Canada's immigration policies and to health and social services policies that have detrimental effects on people with HIV/AIDS.

Many of the project participants commented that ASAP, as the only South Asian HIV/AIDS agency in Canada, must play a leading role in responding to the recommendations. Yet participants also acknowledged that in light of ASAP's modest size and budget, and marginalized status within the broader South Asian community, it could not do this alone. The problems and potential solutions lie in the broader South Asian and mainstream communities and should therefore be addressed by a coalition or consortium.

Conclusion

Many of the project's findings should not come as a surprise to those who work on HIV/AIDS issues in ethno-specific communities. However, perhaps for the first time a clear link has been drawn between the community's silence and denial and the detrimental impact these have on South Asian lives – both within and outside the communities they call home.

In documenting the voices and lived experiences of South Asian people with HIV/AIDS, the project report makes an important contribution to the fight against the denial of HIV/AIDS in South Asian communities. Implementing the recommendations, particularly an aggressive advocacy agenda to implement systemic change, should result in an improved quality of life for South Asians with HIV/AIDS and decreased spread of HIV/AIDS through South Asian communities.

- Meena Radhakrishnan

Meena was a member of the Project Advisory Committee for this project. She is a trained lawyer and social worker currently practising in the area of children's mental health in Toronto.

Copies of the full June 1999 Project Report are available through ASAP, which has also undertaken to translate the report, or significant parts thereof, into various South Asian languages. Please direct inquiries to: ASAP, 126-20 Carlton Street, Toronto ON M5B 2H5, Canada. Tel: 416 599-2727; fax: 416 599-6011.

ASAP is a charitable, non-profit AIDS service organization based in Toronto and working with Canadians of South Asian origin. ASAP was formed in 1989 in response to the deaths of a Tamil-speaking man and woman who had difficulty accessing health-related services from mainstream AIDS organizations. The agency works to promote HIV/AIDS prevention and education in Canadian South Asian communities, supports people with HIV/AIDS, and helps partners, family members, and friends cope with a loved one living with HIV/AIDS.

[1] T de Bruyn. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998.

[2] J Fisher et al. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998.

US: Victory Upheld in Dental Discrimination Case (But New Worries for People with Disabilities)

The US Supreme Court has upheld the judgment awarded to Sidney Abbott, a Maine woman who successfully sued dentist Randon Bragdon for refusing to treat her after learning she was HIV-positive.

The Supreme Court's Recent Decision

The defendant dentist claimed that filling a cavity in her tooth would have posed a "direct threat" to his health and safety, justifying his refusal to deny treatment. Lower courts rejected this argument, and without requiring the case to proceed to trial, ruled in Abbott's favour, ordering the dentist to stop discriminating against HIV-positive people (but not awarding any monetary damages to Abbott).

This decision was appealed up to the Supreme Court in 1998, as reported previously in the *Newsletter*.[1] At that time, the Supreme Court ruled that people with HIV/AIDS could sue for discrimination under the *Americans with Disabilities Act*,[2] and that a health-care provider's conduct in such a case should be judged according to "the objective reasonableness of the views of health care professionals without deferring to their individual judgments."[3] The Supreme Court returned the case to a federal appeals court with this instruction.

Upon review, the 1st US Circuit Court of Appeals ruled in December 1998 that Abbott's original claim for discrimination should be upheld, and that no trial was necessary. The appeals court dismissed the dentist's offered evidence of health risks as "too speculative, or too tangential, or in some instances both, to create a genuine issue of material fact."[4]

In the most recent, and final, decision in this case, in May 1999 the Supreme Court rejected the dentist's final appeal without comment.[5]

What the Decision Means

An excellent summary of *Bragdon* and what it means is provided in a June 1999 issue of *AIDS Policy & Law*.[6] We reproduce a short section of that article:

> Nearly five years of litigation boils down to this:
> - People with HIV can be covered under the *Americans with Disabilities Act* [ADA] even if they have no symptoms of illness. The operative word is "can," because the Supreme Court stopped short of declaring that everyone with HIV was covered. Plaintiffs still must show that HIV substantially limits them in one or more major life activities.
> - The term "major life activities" should be interpreted broadly. It is not restricted to activities that have a "public, daily or economic dimension." Reproduction is a major life activity, and thus is akin to seeing, hearing, working and other functions specifically listed in the government regulations implementing the ADA.
> - A limitation is substantial even if the difficulties are not insurmountable
> - HIV poses a "direct threat" to an uninfected individual only if there is a "significant" risk of harm. The Supreme Court recognized that "few, if any, activities in life are risk free."
> - Determination of risk must be based on "the objective, scientific information available" at the time. In making that assessment, the views of public health experts, such as the Centers for Disease Control and Prevention, "are of special weight and authority." However, a defendant who disagrees with the prevailing consensus may refute those views by citing a "credible scientific basis for deviating from the accepted norm."
> - Health-care professionals who deny treatment based solely on HIV infection cannot escape liability, even if they have a good-faith belief that a significant risk exists.

New Worries

However, since that summary was written, new worries have arisen for persons with disabilities in the US. In three cases decided in June 1999, the Supreme Court ruled that mitigating measures, such as corrective lenses and medications, must be taken into account when determining whether a plaintiff has a disability for purposes of the ADA.[7] The rulings went

against claimants with nearsightedness, monocular vision, and high blood pressure. The Supreme Court held that they did not qualify for the ADA's employment protections because their conditions were correctable.

According to one legal commentator,

> [t]he potential impact of these three decisions on ADA protection for people with HIV/AIDS is difficult to predict, but it is likely that between their holdings and their plentiful dicta they will pose additional stumbling blocks to HIV+ plaintiffs. All three decisions emphasize ... the proposition that each ADA plaintiff must be considered as an individual in determining whether the disability definition is met, including the key question of whether their particular physical impairment substantially limits their own major life activities.[8]

The commentator goes on by saying that "[p]erhaps it is time for Congress to amend the ADA to make it clear that certain conditions are meant to be covered as disabilities."[9] He makes reference to an article by Eichhorn, who suggests that the ADA should be amended to do away with the incredibly litigation-prone definition of disability and replace it with something functional that will achive the remedial purposes of the Act.[10] Disability-rights advocates are also exploring the possibility of a "legislative fix," as reported in *AIDS Policy & Law*.[11] Other commentators, while disappointed by the rulings, are hesitant, saying that efforts to change the ADA could easily backfire. In addition, they argue that the June 1999 Supreme Court decisions will likely not affect persons with HIV/AIDS, whose condition can be easily distinguished from that of a person with myopia, monocular vision, or hypertension.[12]

[1] See R Jürgens. Important legal victories for people with HIV/AIDS in the US. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(2/3): 28-30. See also R Jürgens. Your health is back. Now you may lose your protection against discrimination. *Canadian HIV/AIDS Policy & Law Newsletter* 1997/98; 3(4)/4(1): 3-5.

[2] Pub L No 101-336, 104 Stat 328 (1990) (codified at 42 USC § 12101-13 (1994)).

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

[4] *Abbott* v *Bragdon*, 107 F 3d 934 (1st Cir).

[5] *Abbott* v *Bragdon*, US Supreme Court, Decision No 98-1536, 24 May 1999; R Carelli. Dentist loses appeal in HIV case. *Associated Press*, 24 May 1999, archived at <www.ap.org>.

[6] High court declines to hear second appeal in landmark dental case. *AIDS Policy & Law* 1999; 14(11): 1, 6-7. For another summary, see DS Davis. Bragdon v. Abbott: Who's in? Who's out? *AIDS & Public Policy Journal* 1998; 13(3): 99-102.

[7] *Sutton* v *United Air Lines*, 1999 WL 407488; *Murphy* v *United Parcel Service, Inc*, 1999 WL 407472; *Albertsons, Inc* v *Kirkingburg* 1999 WL 407456.

[8] AS Leonard. Supreme Court ruling on ADA disability definition may undercut protection for people with HIV/AIDS. *Lesbian/Gay Law Notes* Summer 1999, 119-122, at 122.

[9] Ibid.

[10] Ibid, with reference to L Eichhorn. Major litigation activities regarding major life activities: The failure of the "disability" definition in the Americans with Disabilities Act. *NC L Rev* April 1999; 77: 1405.

11. Court rulings prompt talk about amending the ADA. *AIDS Policy & Law* 1999; 14(13): 1, 8.

12. "Mitigating measures" cases won't affect HIV plaintiffs. *AIDS Policy & Law* 1999; 14(13): 9.

Australian Tribunal Rules in Favour of HIV-Positive Football Player

An HIV-positive football player can continue playing his sport after a Victorian tribunal ruled the very low risk of transmitting HIV to other players did not justify his ban.

Amateur footballer Matthew Hall, who complained of discrimination by the Victorian Amateur Football Association (VAFA), was diagnosed HIV-positive in 1996 and decided not to play in 1996 and 1997. During that time he believed he might pose a risk to others if he played. Over those two years, Mr Hall, with the help of his doctor, became more knowledgeable about HIV and transmission risks. In early 1998 he decided there was no reason for him not to play because the risk of infecting anyone on the football field was so low. He discussed his HIV status with the president of his club who, with Mr Hall's consent, wrote "Please note that this player is HIV positive" on his application for registration.

In June 1998 the VAFA advised Mr Hall his application had been rejected due to his HIV status. Mr Hall lodged a complaint with the Equal Opportunity Commission.

On 23 April 1999 the Victorian Civil and Administrative Tribunal, in *Matthew Hall* v *Victorian Amateur Football Association*, ruled that the VAFA had breached section 65(b) of the *Equal Opportunity Act* 1995 (Vic) in refusing to register Mr Hall as a player. The VAFA was ordered to register Mr Hall within 14 days and to refrain from committing any

further contravention of the Act in relation to him. The Tribunal referred for mediation the issue of training and education in relation to HIV, and the requirement that reasonable precautions be taken in respect of HIV transmission.

The Tribunal found that there could be up to 20 VAFA members who are HIV-positive, based on the prevalence of HIV among Australian males aged 15-35. In these circumstances, it held that there was no justification for banning one openly HIV-positive player. The Tribunal heard that the only known case of possible HIV transmission in sport was reported in a letter to *The Lancet* in 1990. Transmission was said to have occurred during a soccer game in Italy, when two players collided. However, public health officials subsequently advised they could not rule out other risk factors, nor could they definitely establish athletic activity as the source of infection.

The VAFA's initial response to the judgment was to announce that it would seek legal advice on an appeal to the Supreme Court, although an appeal was not subsequently lodged. The VAFA also announced that Mr Hall's club would be required to contact the opposition team each week to advise whether or not he would be playing, and published an editorial in its journal criticizing the decision on the grounds that it "failed to deal with the real issue behind the case in that the question of legal liability was largely left untouched." As a result, in May the Equal Opportunity Commission issued a warning against further breaches of the Act.

In the wake of widespread publicity surrounding the hearing, the Commonwealth Department of Health and Aged Care agreed to fund a comprehensive training program, and to produce education resources addressing HIV and hepatitis C prevention for sporting organizations.

Despite his legal victory, Mr Hall still faces significant challenges, including on the football field, where he says he is "hopeful but not confident" of getting to play a game. There is also the problem of finding work. His public stance on discrimination has not enhanced his prospects. Three weeks after he appeared on a television show, he lost his job as floor manager of a Melbourne restaurant where he had worked for three years. His employer was not concerned about his HIV status until Hall began appearing in the media, and patrons started to complain.

Nevertheless, the Victorian AIDS Council, which was granted leave to intervene in the Tribunal hearing, said that the judgment in Mr Hall's case is a "watershed ... [and] will be used right around the world to defend the rights of people with HIV to participate in sport, and that's an enormous contribution Matt [Mr Hall] has made."[1]

[1] Reported in [Australian] *HIV/AIDS Legal Link* 1999; 10(2): 1, 6-7.

Boy with HIV Barred from Karate

The US Supreme Court has been asked to overturn a ruling that allowed the owner of a Virginia karate school to refuse to let an HIV-positive boy participate in classes.[1]

In February 1999 the US 4th Circuit Court of Appeals ruled that a school that teaches "hard-style" Japanese karate was not obligated to accept Michael Montalvo, an HIV-positive boy, for its sparring classes.[2] The Court said that while the chance that Michael would bleed and then transmit the virus was theoretically low, the consequences of infection were so severe that his participation in the classes was too risky.

This was the first time a federal appeals court in the US addressed the question of whether people with HIV have a right under the *Americans with Disabilities Act* to participate in sports and athletics. The ruling may set a precedent for the right of HIV-positive people to participate in certain other sports such as boxing or fencing, but is unlikely to be relevant "to athletic events where the chance of drawing blood is minuscule."[3]

[1] *Montalvo* v *Radcliffe*; US, No 98-1831. Petition for writ of certiorari filed 12 May 1999. Reported in *AIDS Policy & Law* 1999; 14(11): 9.

[2] *Montalvo* v *Radcliffe*; 4th Cir, No 98-1169. Decided 12 February 1999. See: HIV-positive boy can be barred from group karate lessons. *AIDS Policy & Law* 1999; 14(4): 1, 8.

[3] Ibid at 1.

Switzerland – Little Institutional Discrimination

In Switzerland, promoting solidarity toward people with HIV/AIDS is one of the three pillars of the strategy for combating AIDS. A study commissioned by the Swiss Federal Office of Public Health found little evidence of discriminatory practices on the institutional level. Nevertheless, HIV-positive people and those with AIDS continue to face stigmatization and discrimination.[1]

The study, carried out by the Institute for Social and Preventive Medicine of the University of Lausanne, examined the following sources for evidence of discrimination:

- legislation;
- written internal regulations (eg, workplace policies); and
- practices.

The situation in the cantons of Vaud and Geneva was investigated over a period of two years (1996-97). More than 200 interviews were held with representatives from the nine different domains examined (eg, employment, health care, housing, insurance).

No discrimination was found in laws and regulations. Practices revealed de facto discrimination in one case (routine tests carried out with neither permission nor anonymity), and three cases in which discrimination existed but was not necessarily institutional or specific to HIV.

Authorities in the cantons of Vaud and Geneva have promoted policies against HIV/AIDS discrimination since the beginning of the epidemic. The relative lack of discrimination found in this study demonstrates the potential effectiveness of such policies.

For more information about the study, contact the Swiss Federal Office of Public Health, 3003 Berne, Switzerland. Fax: (41 31) 324 9753; or on the web at <www.admin.ch/bag>.

[1] From *spectra* December 1998; 14: 2.

India – No Right to Marry?

Four people, two of them openly HIV-positive, have petitioned the Supreme Court in Mumbai, India, seeking declarations on the right of HIV-positive people to marry, and on medical practitioners' duty of confidentiality in the health-care setting. The petition comes after the case of *Mr X* v *Hospital Z*,[1] **in which the Court ruled that where a person has a "communicable venereal disease or impotence," the right to marry "cannot be enforced through a court of law and shall be treated as a 'suspended right.'"**

For the first time in judicial history anywhere in the world, a court suspended an individual's right to marry. The Court further held that sections 269 and 270 of the Indian Penal Code, which respectively criminalize negligent and malignant acts likely to spread infection of disease dangerous to life, impose a positive duty on a person with HIV not to marry.

The Court also ruled that, while the duty of confidentiality imposed on the medical profession vests a correlative right in the patient to have their confidentiality maintained, that right is subject to certain implied exceptions. One such exception, according to the Court, is where maintenance of the patient's confidentiality gives rise to a health risk in another.

Proceedings were initially brought by Mr X after a doctor at Hospital Z (the respondent) disclosed Mr X's positive HIV status to an acquaintance of X, who in turn disclosed it to X's sister. When the complainant learnt of his HIV-positive status, he traveled to the hospital and confirmed that he was indeed HIV-positive. On returning home, he met his fiancée and her family and the engagement was officially called off. Because of its close-knit structure, the entire community soon found out about the complainant's HIV status, and he was so severely ostracized that he felt compelled to leave his home state. The complainant later filed a complaint with the National Consumer Commission, asking for damages on breach of confidentiality of his medical status by the hospital authorities to third parties. He did not ask for damages for his marriage being called off.

The petition argues that the right to marry is a constitutionally protected right, and is also a fundamental human right recognized by the Universal Declaration of Human Rights and the International Covenant on Civil and Political Rights. It further argues that since the right to marry is a constitutionally protected fundamental right, only a valid statute passed by a competent legislature can abridge it.

The petition relies on studies showing that people with HIV/AIDS can lead normal healthy lives. It argues that where such a person wishes to marry, with the informed consent of the prospective spouse, no restriction should be placed on marriage. This also follows from the fact that transmission of HIV can be prevented by following safe sex practices, and that the risk of perinatal transmission can be significantly reduced through appropriate interventions.

On the issue of confidentiality, the petition argues that even if certain exceptional cases might require a physician to disclose a patient's HIV status to a third party, it is the physician's ethical and moral duty to first inform the patient of the intended course of action, and to adopt the course of action that is least restrictive of the patient's rights.[2]

The full text of the decision, and a comment by the Lawyers Collective HIV/AIDS Unit, can be found at <www.hri.ca/partners/lc> under the "Judgments" section. For more information, contact the Lawyers Collective HIV/AIDS Unit, 7/10 Botawalla Building, 2nd Floor, Horniman Circle, Fort, Mumbai, India 400 023. Email: <aidscaw@bom5.vsnl.net.in>.

[1] (1998) 8 SCC 296.

[2] Reproduced from the [Australian] *HIV/AIDS Legal Link* 1999; 10(2): 22.

Out Of Reach: Anti-Discrimination Law Procedures in Australia

Despite widespread discrimination against people with HIV and/or hepatitis C, few complaints are made using anti-discrimination laws. In a policy paper commissioned by the Legal Working Group of the Australian National Council on AIDS,[1] Julia Cabassi, a policy officer with the AIDS Council of New South Wales, examines barriers to using anti-discrimination remedies. Her findings are strikingly similar to those in a 1998 Canadian discussion paper on HIV/AIDS and discrimination.[2]

Cabassi points out that discrimination against people with HIV/AIDS is well documented, widespread,[3] and can coexist with high levels of factual knowledge about how HIV can be transmitted. The extent of discrimination against people with hepatitis C virus (HCV) is less well documented, but there is a growing body of information indicating that many, if not most, people with HCV experience serious discrimination.[4]

However, despite high levels of discrimination and the existence of anti-discrimination laws that provide mechanisms for individuals to seek redress, Cabassi found that few complaints of HIV/AIDS discrimination are lodged. She identifies numerous barriers to access to, and use of, redress mechanisms, and concludes:

> To be effective, individual complaint systems and remedies need to be accessible, affordable, enforceable and timely.
>
> Even the best anti-discrimination laws on paper must be supported by adequate resources to ensure those charged with responsibility for administering anti-discrimination laws and for supporting access to the remedies provided by those laws, can do so.
>
> "For human rights to be protected through the rule of law, the twin elements of their being expressed in legal terms and that mechanisms exist for their enforcement, must be present."[5]
>
> Individual complaint remedies place a significant burden on individuals to enforce their rights.
>
> Individual solutions have a part to play in a human rights system. This is particularly so where the experience of discrimination is one which falls neatly within the given legislative parameters, where the complainant has the capacity to pursue a remedy, and where the respondent is compliant. But our human rights system needs to empower individuals and communities to use anti-discrimination laws, and it must also be pro-active in addressing systemic discrimination beyond the narrow framework of individual remedies.[6]

Cabassi makes a number of recommendations that, if implemented, would help address the barriers identified. These include elimination of cost disincentives, better resourcing of the human rights system, increases in legal-aid funding, funding for community legal education, and the active promotion of human rights through the conduct of public inquiries into various forms of discrimination.

[1] J Cabassi. Out of reach: Anti-discrimination law procedures. [Australian] *HIV/AIDS Legal Link* 1999; 10(2): 9-17.

[2] T de Bruyn. *HIV/AIDS and Discrimination: A Discussion Paper*. Montréal: Canadian HIV/AIDS Legal Network & Canadian AIDS Society, 1998; see also the summary of the paper in the *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(2/3): 25-28.

[3] *Discrimination – The Other Epidemic: Report of the Inquiry into HIV/AIDS Related Discrimination*. NSW Anti-Discrimination Board, April 1992; A Kippax et al. *Discrimination in the Context of HIV/AIDS: Disease and Deviance*. Macquarie University AIDS Research Unit, NSW, July 1991; A Malcolm et al. HIV related stigmatization and discrimination – its form and context. *Critical Public Health* 1998; 8(4); E Herdman et al. *Institutional Discrimination: Critical Ethnography of HIV/AIDS Related Discrimination in a Hospital Setting*. National Centre in HIV Social Research, 1995.

[4] D Burrows, B Bassett. *Meeting the Needs of People in Australia Living with Hepatitis C*. National Hepatitis C Councils Education Reference Group, August 1996; Hepatitis C Council of NSW. *Submission to the NSW Parliamentary Standing Committee on Social Issues – Inquiry into Hepatitis C*. September 1997, at 9-12.

[5] D Kinley (ed). *Human Rights in Australian Law*. Sydney: The Federation Press, 1998, at 18.

[6] Cabassi, supra, note 1 at 16-17.

HIV/AIDS IN PRISONS

HIV/AIDS in Prisons: New Developments

Since the last issue of the *Newsletter*, which reported, among other things, about a study on HIV and hepatitis C seroprevalence in a Canadian prison[1] and about needle distribution in Swiss prisons,[2] there have been new developments in several jurisdictions in the area of HIV/AIDS and prisons. Unfortunately, the news is not always good.

In Canada, the number of federal inmates *known* to be living with HIV or AIDS reached 200 for the first time in April 1999, an increase of nearly 100 percent since 1994.[3] At the same time, a document compiling various reports on an HIV outbreak intervention at a federal prison was released,[4] but the prison systems, federal and provincial, have yet to act on many of the recommendations made in various reports that would assist them in preventing such outbreaks in the first place.[5] In the United States, courts in many states have had to decide about whether the (lack of adequate) treatment for HIV that prisoners are receiving constitutes an infringement of their constitutional rights. Most of the prisoners won their cases. However, the widespread denial of care, treatment, and support revealed in such cases is a cause of grave concern, revealing as it does that prisoners are considered by many as second-class citizens undeserving of equal access to medical treatment. In the United Kingdom, a court had to decide about whether prisoners should have acces to condoms. It did decide that the particular prisoner who brought the case should not have been denied access to condoms. However, in a decision that could be funny if it was not so sad, it said that access to condoms needed to be given only to "genuine homosexuals," on their request. One wonders what proof will be required? Finally, in Australia, the Australian Medical Association expressed its alarm about the "sickening health standards [in prison] which do nothing for a prisoner's ability to cope with everyday life on release, and put other people in society at risk."[6] The Association called on all governments to address the "appalling health problem" of HIV and hepatitis transmission in prisons, asserting that prisoners' health was a community responsibility and that "society needs to come out of denial thinking that a prison wall solves the problem."

Canada

200 and counting ...

As reported by the Correctional Service of Canada (CSC), the number of reported cases of HIV/AIDS in Canada's federal prison system rose to 200 in April 1999 (it had been 14 in January 1989 and 159 in March 1996).[7] This means that far more than one percent of all federal prison inmates are known to be HIV-positive. The actual numbers may be even higher: the reported cases, provided by CSC, include only cases of HIV infection and AIDS *known* to CSC, but many inmates may not have disclosed their HIV status to CSC, or may not know themselves that they are HIV-positive.

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Report on disease outbreak containment intervention

A report has become available on a disease outbreak containment investigation undertaken in a federal prison in Nova Scotia.[8] In 1996 two HIV-

and HCV-positive inmates at Springhill Institution informed health-care staff that they had shared needles and injection equipment with a significant number of other inmates. A disease outbreak containment intervention was initiated, and 17 contacts of the two inmates were tested. In addition, a follow-up epidemiological study was conducted and a generic outbreak investigation plan developed. However, no attempt was made to prove that, as a result of sharing needles and injection equipment with the known positive inmates, other inmates had contracted HIV or HCV while in prison. The report provides background information about the institution and the role of public health in Nova Scotia; describes the outbreak containment intervention, suggesting lessons to be learned from it and a generic model for identifying potential future outbreaks; presents the results of an epidemiological study undertaken at the institution; and makes numerous recommendations, including that CSC implement a comprehensive harm-reduction strategy in correctional institutions.

Australia

Condoms and needles for Victorian prisons

As reported in the Australian press in December 1998, a parliamentary committee in Victoria was considering the free provision of condoms and clean needles in prisons as a measure to prevent the spread of hepatitis C.[9]

The issue of harm minimization in the context of illegal drug use in Victorian prisons was raised by the Victorian Justice Department, which said that hepatitis C was "raging" in prisons.

Condoms and needles in prisons in Tasmania

Tasmanian Health Minister Judy Jackson welcomed the Australian Medical Association report recommending the distribution of condoms and injecting equipment to prisoners,[10] saying that the government has a duty to protect inmates from disease because of the health risk they pose to society on release.

"There is a recognition that when people are in prison their health status is important to the general community because at some stage most of them actually come back into the community," she said. "We don't want people coming back in the community with hepatitis C or AIDS and we, I believe, have a responsibility to make sure that we protect the rest of the community."

Liberal MHA Matt Sith urged the government not to delay distributing condoms and implementing a needle exchange program, saying: "It's an issue of life and death and we have to look at the earliest possible implementation program."[11]

Condoms in Queensland prisons

The Queensland Corrective Services Commission announced on 18 March 1999 that condom vending machines will be trialed in three maximum-, medium-, and low-security prisons in a bid to reduce the rate of sexually transmitted diseases.

Dr Tony Falconer, Health and Medical Consultant for the Corrective Services Commission, said: "Ultimately it is a health initiative that has two major benefits – a safer environment for both staff and prisoners and secondly, decreasing the transmission of communicable diseases to the wider community as most prisoners will be released."

Dr Falconer said that the Commission's board had expressed interest in the trials after monitoring similar programs in other states, including New South Wales, where condoms are available in prisons.[12]

United States

New York: State prison system fails to provide adequate care

The New York States AIDS Advisory Council found that the state's prison health systems have failed to provide adequate HIV prevention and treatment. The Council recommended that responsibility for prisoners' health be transferred to the state department of health.

Community organizations say there are high levels of unsafe sex among the state's 70,000 prisoners, around 8000 of whom are believed to be HIV-positive.

In response to criticism, a spokesperson for the Department of Correctional Services said there had been a sharp drop in the number of AIDS-associated deaths in the prison system since 1995, and claimed that this attested to the quality of care in the prison system.[13]

New York: No right to nutritional supplements

A New York prison inmate is not entitled to receive a specific nutritional supplement just because he has HIV, the 2nd US Circuit Court of Appeals said.[14]

The inmate alleged that doctors and nurses at the Attica Correctional Facility wrongfully refused to give him Ensure, a brand-name product, as part of his treatment for HIV disease. The inmate said the supplement was needed because he was losing weight and his CD4 T-cell count was falling. According to him, the refusal

amounted to deliberate indifference to his medical needs, in violation of his 8th Amendment right to be free of cruel and unusual punishment.

The 2nd Circuit said that the inmate's assertions were unfounded and his legal theory flawed. Uncontested affidavits supplied by the prison medical staff showed that the inmate would not take his HIV medications as prescribed and instead insisted on being treated with Ensure. The staff refused to oblige because the inmate's weight was stable and the supplement was not medically necessary.

The state prison system in Texas will remain under judicial supervision in part because of lingering doubts about the adequacy of HIV treatment and officials' response to rape by inmates.

Texas: State prison system to remain under judicial supervision

The state prison system in Texas will remain under judicial supervision in part because of lingering doubts about the adequacy of HIV treatment and officials' response to rape by inmates.[15]

US District Judge William Wayne Justice said that the state corrections system had achieved remarkable progress since 1972, when inmates sued because medical care was so abysmal that they sometimes had to perform surgery on each other. Following a 1981 consent decree, the Texas Department of Correctional Justice began a major overhaul of policies and practices in a wide range of areas, including health services and classification practices. The Department, saying that it had fulfilled the terms of the agreement, asked the judge to end the court's supervision of prison operations. However, the judge said that despite the overhaul he remained unconvinced that the prison system had improved to such an extent that it no longer violated the inmates' right to be free from cruel and unusual punishment.

After hearing 19 days of testimony from more than 60 witnesses, the judge issued a 167-page opinion that left intact the consent order, as modified in 1992. Although the judge said that the Department had made giant strides in improving care for HIV-positive inmates, he still had some concerns. For example, lockdowns prevented inmates from receiving their medications, and long waits at pharmacy lines discouraged them from staying on anti-HIV drugs. Inmates who did not adhere to their regimens were taken off their drugs, but staff often made no attempt to explore the reasons for their lack of adherence. Also, medical orders issued by university doctors were ignored or neglected by prison personnel. Some inmates were required to perform work or activities against their doctors' orders.

The judge also held that prison officials failed to take reasonable measures to protect vulnerable inmates from other, predatory prisoners.

Texas officials plan to ask the 5th US Circuit Court of Appeal to reverse the ruling.

Georgia: Jail must remedy substandard HIV care for inmates

A consent decree signed by a federal judge in Atlanta on 16 April 1999 seeks to end the substandard medical care provided to HIV-positive jail inmates in Fulton County, Georgia.

US District Judge Marvin Shoob approved an arrangement worked out by attorneys for the jail and for eight inmates, who had begun their suit for class-action injunctive relief just eight days earlier.

The suit alleged that the jail violated the inmates' Eighth Amendment constitutional right to be free from cruel and unusual punishment and their Fourteenth Amendment right to equal protection under the law. It said that the jail and its health-care contractor failed to provide the continuity of care that is required in the treatment of HIV disease, and pointed out that suboptimal care can render HIV resistant to all drugs. The eight inmates said employees at the jail's medical unit lost antiretroviral medicines or allowed supplies to run out. Sometimes the jail administered medication that was not consistent with the treatment regimens that inmates were receiving prior to incarceration. One inmate did not receive his medicines until 30 days after telling staff that he needed them.

In the consent decree, the jail promises to give HIV-positive inmates immediate access to acute medical care and to any treatment regimen consistent with standards of care set forth by the federal Department of Health and Human Services and the National Commission on Correctional Health Care.[16]

Mississippi: Judge says prison must obey treatment guidelines

For the first time, a federal court has held that prison inmates are entitled to the quality of HIV medical care outlined in treatment guidelines

issued by the National Institutes of Health (NIH).[17]

In a preliminary injunction issued on 16 July 1999, US Magistrate Judge Jerry A Davis placed the Mississippi Department of Corrections on a schedule for complying with the NIH standards, saying that the "HIV-positive inmates are entitled to a degree of care that will not hasten their death, and the defendants are obligated to provide it."

Since June 1997 the NIH has called for the use of at least three antiretroviral drugs, including a protease inhibitor, whenever treatment is begun. Nevertheless, Mississippi prison officials maintained a policy of prescribing a two-drug regimen until January 1999. Inmates received a protease inhibitor only if they could prove that they had been adhering to that regimen for at least six months. In addition, the prison's medical staff changed drug regimens without ever determining whether the combination was actually working: the prison did not perform regular viral load tests. Finally, inmates were denied access to medications to prevent opportunistic infections.

Judge David said that the inmates were entitled "at a minimum" to the degree of care outlined in the NIH guidelines, and added: "Simply because they are incarcerated should not subject these inmates to a level of care that will significantly lower their chances of surviving with the virus, especially since the treatment that will give maximum suppression is known."

Maine: Denial-of-care suit settled

On the eve of trial, a health-care provider for a county jail in Maine agreed to settle a lawsuit alleging that it had deprived an HIV-positive inmate of antiretroviral medications in an attempt to save money. The inmate was confined to a county jail in November 1997 after he missed a court date. Although he and his doctor had told the medical provider that his HIV medications could not be interrupted, no drugs were administered during the first three days he spent behind bars. The lawsuit charged that the contractor had violated constitutional guarantees against deliberate indifference and contravened the *Americans with Disabilities Act* by providing a different quality of care for inmates based on HIV status.

Prison Health Services Inc settled the suit the day before trial was to begin. The terms of the agreement were not disclosed.[18]

California: TB threat to prisoners with HIV

California's Corrections and Health Services departments have developed rigorous detection and rapid contact-tracing procedures for tuberculosis (TB) following the investigation of two outbreaks of TB in the HIV units of state prisons, which then spread to the community.

Because HIV infection severely weakens the immune system, people with both HIV and TB have a hundred-fold greater risk of developing active TB disease, which can then spread to others.

During the investigation, 32 cases of TB were confirmed among HIV-positive inmates, parolees, and a visitor. The investigation found evidence of the rapid cycle of TB transmission in prison environments, and concluded that early diagnosis, isolation of infectious TB cases, and effective treatment of HIV-positive inmates is needed to cure TB disease and to minimize outbreaks.[19]

Court affirms right to confidentiality

People do not lose their right to maintain the confidentiality of their HIV status upon being imprisoned, a federal appeals court ruled in a case brought by an HIV-positive transsexual, Ms Devilla.

In December 1991, while escorting Devilla to the prison's medical unit, a corrections officer told a co-worker in the presence of other inmates that Devilla had HIV and had undergone a male-to-female sex-change operation. As word about her infection and transsexual status circulated, Devilla became the target of harassment by guards and prisoners.

The US 2nd Circuit of Appeals, in *Powell* v *Schriver*,[20] stated that "[i]n our view, it was as obvious in 1991 as it is now that under certain circumstances, the disclosure of an inmate's HIV-positive status and – perhaps more so – her transsexualism could place that inmate in harm's way." According to the Court, disclosure of one's HIV status or transsexualism is permissible for legitimate penological purposes, such as medical treatment. However, in the case at hand, the revelation served only as "humor or gossip" for corrections employees.

As for Devilla's privacy claims, the Court held that Devilla did have an interest in maintaining the confidentiality of her HIV infection and gender transformation. An individual whose HIV seropositivity is revealed may be exposed "not to understanding or compassion, but to discrimination and intolerance," the Court said. The desire by some transsexuals to maintain the "excruciatingly private and intimate nature" of their gender change "is really beyond debate."

Prisoner allowed to sue using pseudonym

An HIV-positive plaintiff in a civil suit against the City of Milwaukee will be allowed to continue the litigation under a pseudonym because AIDS stigma still remains potent, a federal judge in Wisconsin said.[21]

No right to protection?

US Senator Strom Thurmond has revived a bill aimed at excluding prison inmates and pretrial detainees from protections under the *Americans with Disabilities Act* (ADA). The bill seeks to reverse the US Supreme Court's ruling in *Pennsylvania Department of Corrections* v *Yeskey*,[22] which held that inmates in state prisons are covered by the ADA.

Thurmond introduced a similar bill in July 1998, shortly after the *Yeskey* decision was announced by a unanimous court. The bill died with the adjournment of the 105th Congress in 1998. In a speech on the Senate floor, Thurmond argued, among other things, that accommodating inmates with disabilities such as AIDS, psychological disorders, or mental retardation, would strain prison budgets. He said:

> Even with prison populations rising, the people do not want more of their money spent on prisoners.... The public is tired of special privileges for prisoners.[23]

Supreme Court asked to rule on segregation

The American Civil Liberties Union (ACLU) has asked the US Supreme Court to overturn a ruling that allows Alabama prison officials to segregate inmates by HIV status and deny HIV-positive inmates a range of prison services and programs.[24]

The ACLU seeks to reverse the ruling of the 11th Circuit Court of Appeals, which in *Onishea* v *Hopper*[25] held that integrating prison programs and services would place uninfected inmates at "significant risk" of contracting HIV.

More than 70 programs were at issue, including literacy training, vocational and college preparatory courses, sports competitions, and worship services.

Previously, the 11th Circuit had held that a "remote, theoretical risk" was insufficient to bar an HIV-positive person from access to public services. *Onishea* changed that. In that case, the Court said that the risk was significant even if the possibility of transmission was low, because of the consequences of infection: "It is the potential gravity of the harm that imbues certain odds of an event with significance," the majority said. "Thus, when the adverse event is the contraction of a fatal disease, the risk of transmission can be significant even if the probability of transmission is low: Death itself makes the risk 'significant.'" The majority thus held that, as a matter of law, HIV presents a "significant risk" whenever an event presents an opportunity for HIV transmission to occur, provided that the danger be rooted in sound medical opinion. The majority was harshly criticized for adopting an "any risk" standard by Judge Barkett who, writing for himself and Chief Judge Hatchett, pointed out that the ruling "is in direct conflict with governing Supreme Court precedent" in its 1987 ruling on *School Board of Nassau County* v *Arline*.[26]

In asking the Supreme Court to overturn the ruling, the ACLU said that the rationale used by the majority could be used to exclude people with HIV from jobs, education, and health care because of the "purely hypothetical and speculative possibility" that they might transmit HIV to others.

A British judge ruled on 4 July 1999 that "actively homosexual" prisoners should be prescribed condoms to cut the risk of HIV and other sexually transmitted diseases.

United Kingdom

Condoms for "genuine homosexuals"

A British judge ruled on 4 July 1999 that "actively homosexual" prisoners should be prescribed condoms to cut the risk of HIV and other sexually transmitted diseases.[27]

But Justice Latham, ruling on a legal challenge by a gay prisoner, said that condoms need not be available on demand and that the Prison Service was entitled to maintain its policy of not being seen to encourage homosexual activity. "It seems to me that whenever a prison medical officer is satisfied that a request for condoms is from a genuine homosexual who is intent on indulging in what would otherwise be unsafe sex, he should prescribe condoms," the judge said.

The challenge was brought by Glen Fielding, who was refused condoms while serving a sentence at a prison in central England. The judge held that while there was nothing wrong with the Prison Service's condom policy, it had been misapplied in Fielding's case. "So long as the Prison Service continues to take the view that there should be the

control inherent in the policy, the policy itself might be reformulated so as to make clear what the limits of the prison medical officers' discretion should be," Justice Latham said.

Responding to the judgment, the Prison Service said that while the judge had upheld its four-year-old policy, it was working toward new instructions on the issuing of condoms in order to make the implementation of the policy more effective and consistent across the prison system.

In 1995 the Prison Service of England and Wales released a *Review of HIV and AIDS in Prison*,[28] recommending, among other things, that condoms, dental dams, and lubricant be made easily accessible to prisoners. All of the Committee's 39 recommendations were accepted, with the exception of the recommendation on condoms. The policy of the Prison Service became to make condoms available only on prescription "if in the clinical judgment of the doctor there is a risk of HIV infection."

- Ralf Jürgens

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

[1] 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.

[2] D Zeegers Paget. Needle distribution in the Swiss prison setting: a breakthrough? *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(2/3): 60-61.

[3] Correctional Service Canada. Reported cases of HIV/AIDS in federal penitentiaries 1999. Ottawa: CSC, March and April 1999. For more information, see also HIV/AIDS in Prisons Info Sheet 1: *HIV/AIDS and Hepatitis C in Prisons: The Facts*. Montréal: Canadian HIV/AIDS Legal Network, 1999.

[4] Correctional Service Canada. *Springhill Project Report*. Ottawa: CSC, May 1999.

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

[6] Reported in *Courier Mail* (Brisbane), 19 October 1998, and cited in C Puplik. The last of my brethren. [Australian] *HIV/AIDS Legal Link* 1999; 10(1): 13-15 at 13.

[7] Supra, note 3.

[8] Supra, note 4.

[9] Reported in [Australian] *HIV/AIDS Legal Link* 1999; 10(1): 4, with reference to *Herald-Sun* (Melbourne), 4 December 1998.

[10] Supra, note 5.

[11] Reported in [Australian] *HIV/AIDS Legal Link* 1999; 10(1): 5, with reference to *Hobart Mercury*, 19 March 1999.

[12] Reported in [Australian] *HIV/AIDS Legal Link* 1999; 10(1): 5-6, with reference to *Courier Mail* (Brisbane), 19 March 1999.

[13] Reported in [Australian] *HIV/AIDS Legal Link* 1999; 10(1): 22, with reference to *New York Times*, 18 February 1999.

[14] *Polanco* v *Dworzack*, No 98-2965 (2nd Cir, 5/28/99). Reported in *AIDS Policy & Law* 1999; 14(15): 10; *Lesbian/Gay Law Notes* Summer 1999, at 123.

[15] *Ruiz* v *Johnson*, SD Texas, No H-78-087. Order signed 1 March 1999. Reported in *AIDS Policy & Law* 1999; 14(7): 6.

[16] *Foster* v *Fulton County*, ND Ga, No 1:99-CV-0900. Lawsuit filed 8 April 1999. Consent decree signed 16 April 1999. Reported in *AIDS Policy & Law* 1999; 14(8): 5.

[17] *Gates* v *Fordice*, No 4:71CV6-JAD, consolidated with Moore v Fordice, No 4:90CV125-JAD (ND Miss, 16 July 99). Reported in *AIDS Policy & Law* 1999; 14(14): 1, 8.

[18] *McNally* v *Prison Health Services Inc*, No 98-290-P-C (D Maine, settlement announced 26 June 1999).

[19] Reported in [Australian] *HIV/AIDS Legal Link* 1999; 10(1): 22-23, with reference to: Tuberculosis outbreaks in prison housing units for HIV-infected inmates – California 1995-1996. *Morbidity and Mortality Weekly Report*, 5 February 1999; 47(4): 79-82, retrievable at <http://www.cdc.gov/epo/mmwr/preview/mmwrhtml/00056381.htm>.

[20] 2nd Cir, No 97-2851. Decided 2 April 1999. Reported in *AIDS Policy & Law* 1999; 14(8): 2; *Lesbian/Gay Law Notes* May 1999, at 66.

[21] *Roe* v *City of Milwaukee*; ED Wis, No 98-C-462. Decided 23 February 1999. Reported in *AIDS Policy & Law* 1999; 14(7): 11; *Lesbian/Gay Law Notes* April 1999, at 60-61.

[22] 524 US 206 (1998).

[23] Reported in *AIDS Policy & Law* 1999; 14(5): 11.

[24] *Davis* v *Hopper*; US, case number not yet assigned, petition filed 20 May 1999. Reported in *AIDS Policy & Law* 1999; 14(11): 3.

[25] 11th Cir, No 96-6213. Decided 7 April 1999. See: Court redefines standard for HIV transmission risk. *AIDS Policy & Law* 1999; 14(8): 1, 6-9; 11th Circuit ruling in HIV prison case a set-back for prisoners with HIV. *Lesbian/Gay Law Notes* May 1999, at 1-2.

[26] 480 US 273 (1987).

[27] *R* v *Secretary of State for the Home Department, Ex parte Fielding*, England and Wales Queen's Bench Divisional Court, [1999] TNLR No 543.

[28] AIDS Advisory Committee. *The Review of HIV and AIDS in Prison*. London, England: HM Prison Service of England and Wales, 1995.

Essential Resource on HIV/AIDS in Prisons

In July 1999 the Canadian HIV/AIDS Legal Network launched a new series of 13 info sheets on HIV/AIDS in prisons. The info sheets provide concise, up-to-date, accessible information on HIV/AIDS and hepatitis C in prisons in Canada and internationally.

The 13 info sheets are:

1. HIV/AIDS and Hepatitis C in Prisons: The Facts
2. High-Risk Behaviours behind Bars
3. HIV Transmission in Prison
4. Prevention: Condoms
5. Prevention: Bleach
6. Prevention: Sterile Needles
7. Prevention and Treatment: Methadone
8. Care, Treatment, and Support
9. A Comprehensive Strategy
10. Aboriginal Prisoners and HIV/AIDS
11. Women Inmates and HIV/AIDS
12. A Moral and Legal Obligation to Act
13. Essential Resources

We reproduce info sheet 13, which provides information about a number of selected, essential resources – articles, books, reports, and newsletters that provide crucial information and/or recommendations on HIV/AIDS in prisons.

Canadian Resources

Canadian Centre on Substance Abuse & Canadian Public Health Association. *HIV, AIDS and Injection Drug Use: A National Action Plan*. Ottawa: The Centre & The Association, 1997.
The national action plan on HIV/AIDS and injection drug use emphasizes that "Canada is in the midst of a public health crisis concerning HIV and AIDS, and injection drug use," and that "[i]mmediate action is required at all levels of governmental and community leadership." With regard to HIV/AIDS in prisons, it states that "conditions in correctional settings must be improved" by increasing access to methadone treatment and conducting "pilot programmes of needle exchange in federal and provincial correctional settings." Available at the website of the Canadian Centre on Substance Abuse (www.ccsa.ca) or through the Canadian HIV/AIDS Clearinghouse (tel: 613-725-3769; email: aids/sida@cpha.ca).

Correctional Service Canada. *HIV/AIDS in Prisons: Final Report of the Expert Committee on AIDS and Prisons*. Ottawa: Minister of Supply and Services Canada, 1994.
One of the most comprehensive reports on issues raised by HIV/AIDS and by drug use in prisons. It contains 88 recommendations on how to prevent HIV transmission in prisons and on care for prisoners with HIV/AIDS. Still extremely relevant, but must be read together with Jürgens, 1996, infra. Also available: *HIV/AIDS in Prisons: Summary Report and Recommendations* (the summary version of the report); and *HIV/AIDS in Prisons: Background Materials* (includes a review of Canadian legal cases dealing with issues raised by HIV/AIDS in prison, a summary of the prison policies of Canadian provinces and territories and of selected foreign countries, and an analysis of the legal and ethical issues raised by protecting confidential medical information pertaining to prisoners).

Correctional Service Canada. *Finding Out: What You Need to Know. A Guide for Inmates Living with HIV*. Ottawa: CSC, 1994.
A guide for inmates with HIV/AIDS, including sections dealing with legal issues: disability and insurance, discrimination, how to file a complaint, how to find a lawyer, medical powers of attorney, living wills, and wills.

Correctional Service Canada. *1995 National Inmate Survey: Final Report*. Ottawa: CSC (Correctional Research and Development), 1996, No SR-02.
The results of a CSC survey of 4285 inmates, confirming that a high proportion of inmates engage in high-risk behaviours.

R Elliott. Prisoners' Constitutional Right to Sterile Needles and Bleach. Appendix 2 in R Jürgens. *HIV/AIDS in Prisons: Final Report*. Montréal: Canadian HIV/AIDS Legal Network and Canadian AIDS Society, 1996.
Do prisoners have a right to the means that would allow them to protect themselves against contracting HIV and other diseases in prisons? Can prison systems be forced to provide condoms, bleach, and sterile needles? Can and should the law be used to achieve change in prison HIV/AIDS policies? The article discusses these questions. In particular, it analyzes whether denying prisoners access to sterile needles is a violation of their constitutional rights. Available at <www.aidslaw.ca/elements/APP2.html>.

R Jürgens. *HIV/AIDS in Prisons: Final Report*. Montréal: Canadian HIV/AIDS Legal Network and Canadian AIDS Society, 1996.
A comprehensive 150-page report, summarizing the history of HIV/AIDS in prisons in Canada and internationally. Includes sections on prevalence of risk behaviours in prisons, HIV transmission behind bars, needle exchange programs, methadone maintenance treatment, and more. Argues that prison systems have a moral and legal obligation to act to reduce the risk of further spread of HIV behind bars, and to provide appropriate care, treatment, and support. Includes hundreds of references and a substantial bibliography. Available at <www.aidslaw.ca/elements/download1.html> and through the Canadian HIV/AIDS Clearinghouse.

Prisoners with HIV/AIDS Support Action Network. *HIV/AIDS in the Male-to-Female Transsexual and Transgendered Prison Population: A Comprehensive Strategy*. Toronto: PASAN, 1998.
Discusses the risk of HIV infection for transsexual and transgendered prisoners, summarizes the major issues confronting male-to-female transsexual and transgendered prisoners, and makes recommendations for action in the following areas: prevention of HIV transmission; injection drug use and HIV; medical and support services; human rights and confidentiality; and aftercare. For copies, contact PASAN, 489 College Street, Suite 405, Toronto, Ontario M6G 1A5 (tel: 416 920-9567; email: pasan@interlog.com).

International Resources

American College of Physicians, National Commission on

Correctional Health Care, and American Correctional Health Services Association. The crisis in correctional health care: the impact of the national drug control strategy on correctional health services. ***Annals of Internal Medicine*** **1992; 117(1): 72-77.**
A joint position paper pointing out how existing problems in prisons in the US have been exacerbated by the war on drugs. The paper recommends that the drug-control strategy, with its emphasis on incarceration, be reconsidered; that correctional health-care budgets reflect the growing needs of the inmate population; that correctional health care be recognized as an integral part of the public health sector; that correctional care evolve from its present reactive "sick call" model into a proactive system that emphasizes early disease detection and treatment, health promotion, and disease prevention.

RL Braithwaite, TM Hammett, RM Mayberry. P*risons and AIDS: A Public Health Challenge*. San Francisco: Jossey-Bass, 1996.
Provides information about the frequency of sexual contact, drug use, needle sharing, and tattooing in prisons in the US; analyzes existing educational and prevention efforts; and recommends strategies for developing improved prevention programs, including for young offenders and for ethnic-minority inmates. Includes a guide to education and prevention resources in the US.

K Dolan, A Wodak. An international review of methadone provision in prisons. ***Addiction Research*** **1996; 4(1): 85-97.**
Few papers have appeared documenting the provision of methadone in prison systems. This is probably the most comprehensive review, based on correspondence with prison authorities in a number of countries.

NN Dubler, VW Sidel. On research on HIV infection and AIDS in correctional institutions. ***The Milbank Quarterly*** **1989; 67(2): 171-207.**
The article discusses the problems involved in conducting research on prisoners. It concludes that, although a prison setting precludes voluntary and uncoerced choice, prisoners should be permitted to choose to participate in research, including therapeutic trials with no placebo arm that hold out the possibility of benefit.

European Network on HIV/AIDS and Hepatitis Prevention in Prisons. ***Final Report on the EU Project European Network on HIV/AIDS Prevention in Prisons*****. Bonn and Marseille: The Network, 1997.**
The proceedings of the first seminar of the European Network for HIV/AIDS and Hepatitis Prevention in Prison, held in Marseille on 20 June 1996, contain a review of literature on HIV risk behaviours in prisons and an overview of the situation in six European countries: Germany, Scotland, France, Italy, the Netherlands, and Sweden. For a copy, contact WIAD e.V., Godesberger Allee 54, 53175 Bonn, Germany. The French report, *L'infection à VIH en milieu carcéral: épidémiologie, prévention, aspects éthiques et juridiques*, can be ordered from: Service études de l'O.R.S., 23 rue Stanislas Torents, 13006 Marseille, France. Tel: (33-4) 91-59-89-00; fax: (33-4) 91-37-48-24. See also: **European Network on HIV/AIDS and Hepatitis Prevention in Prisons. 2.** ***Annual Report – European Network on HIV/AIDS Prevention in Prisons*****. Bonn and Marseille: The Network, 1998** (the second report by the European Network, with detailed information regarding HIV/AIDS and hepatitis in prisons in 16 European countries and an updated European bibliography on HIV/AIDS in prison).

TM Hammett, P Harmon. ***1997 Update: HIV/AIDS, STDs, and TB in Correctional Facilities*****. Washington, DC: US Dept of Justice, National Institute of Justice and US Department of Health and Human Services, Centers for Disease Control and Prevention, 1998.**
Summarizes the situation with regard to HIV/AIDS, STDs, and TB in prisons in the US. Updated yearly.

Joint United Nations Programme on AIDS. ***Prisons and AIDS: UNAIDS Technical Update*****. Geneva: UNAIDS, 1997; and** ***Prisons and AIDS: UNAIDS Point of View*****. Geneva: UNAIDS, 1997.**
An extremely useful pair of documents on HIV/AIDS and drug use in prisons around the world, with basic information about the issues, challenges, responses, resources, and UNAIDS' point of view. This is probably the best summary available on HIV/AIDS and drug use in prisons. Available at www.unaids.org and in English, French, Russian, or Spanish from a UNAIDS Information Centre (for more info, contact UNAIDS at unaids@unaids.org; tel: 41-22 791-4651).

Joint United Nations Programme on HIV/AIDS. United Nations Commission on Human Rights (Fifty-second Session, item 8 of the agenda). HIV/AIDS in Prisons – Statement by the Joint United Nations Programme on HIV/AIDS (UNAIDS). Geneva, April 1996.
This statement by UNAIDS to the Commission on Human Rights argues

that the treatment of prisoners in many countries constitutes a violation of the prisoners' human rights. UNAIDS urges all governments to use the World Health Organization's guidelines on HIV/AIDS in prisons (see infra) in formulating their prison policies and offers assistance to any government wishing to implement the guidelines. Available at <www.unaids.org/unaids/rights/prisons.htm>.

J Nelles, E Fuhrer (eds). *Harm Reduction in Prison: Strategies Against Drugs, AIDS and Risk Behaviour*. Berne: Peter Lang AG, 1997.
A summary of the proceedings of a symposium on harm reduction in prisons, held in Berne, Switzerland, in March 1996. At the symposium, the initial results of the first scientifically evaluated needle exchange project in prison were presented and discussed to "prepare a scientific basis for subsequent political decisions." Articles in English, French, and German.

J Nelles, T Harding. Preventing HIV Transmission in Prison: A tale of medical disobedience and Swiss pragmatism. *The Lancet* 1995; 346: 1507.
Describes how Dr Franz Probst, a part-time medical officer working at Oberschöngrün prison in the Swiss canton of Solothurn, began distributing sterile injection material without informing the prison director: the world's first distribution of injection material inside prison began as an act of medical disobedience.

S Rutter et al. *Is Syringe Exchange Feasible in a Prison Setting? An Exploration of the Issues*. Technical Report No 25. Sydney: National Drug and Alcohol Research Centre, 1995.
A study conducted to consider the issues raised by syringe exchange programs in prison and to assess their possible benefits, adverse consequences, and the feasibility of implementing them. The study found that needle and syringe exchange is feasible in Australian prisons.

D Shewan, JB Davies (eds). *Drug Use and Prisons: An International Perspective*. Amsterdam: Harwood Academic, 1999.
Provides a comprehensive account of patterns of drug use and risk behaviours in prisons, and of the different responses to this feature of prison life. Contains articles from Europe, North and South America, Africa, and Australia. A must-read. To be published in late 1999.

PA Thomas, M Moerings (eds). *AIDS in Prison*. Aldershot, UK, and Brookfield, Vermont: Dartmouth Publishing Company, 1994.
A collection of articles on prison policies and practice in ten countries (Norway, Germany, Poland, England & Wales, the Netherlands, Belgium, Italy, Spain, Canada, USA). The laws and procedures and the extent of their application within the prison systems are reviewed, and issues such as drug use by prisoners, sexual activity in prisons, early release, drug-free units, education, and the availability of condoms and bleach are addressed.

World Health Organization. WHO Guidelines on HIV Infection and AIDS in Prisons. Geneva: WHO, 1993 (WHO/GPA/DIR/93.3).
This 10-page article written from a public health perspective proposes standards for prison authorities in efforts to prevent HIV transmission and provide care to those with HIV/AIDS in prisons. Available at <www.aidslaw.ca/elements/APP5.html>.

Newsletters

AIDS Policy & Law
A US biweekly newsletter on legislation, regulation, and litigation concerning AIDS. Contains short summaries of US developments, mainly lawsuits. For info, contact *AIDS Policy & Law* (tel: 215-784-0860).

Canadian HIV/Policy & Law Newsletter
Required reading for all those working on, or interested in, HIV/AIDS in prisons. Provides regular updates and feature articles on policies and programs from around the world. Bilingual (English and French). For info, contact the Canadian HIV/AIDS Legal Network (tel: 514-397-6828 ext 227; email: info@aidslaw.ca). Also available at <www.aidslaw.ca/Newsletter/bulletinE.html>.

HIV/AIDS Legal Link
Regular updates on HIV/AIDS in prisons in Australia. For info, contact the *HIV/AIDS Legal Link* (tel: 61-2-9281-1999; email: afao@rainbow.net.au).

Hepp News
Provides HIV updates designed for practitioners in the correctional setting. Targets correctional administrators and HIV/AIDS care providers, with up-to-the-moment information on HIV treatment, efficient approaches to administering such treatments in the correctional environment, and US and international news related to HIV in prisons. Published monthly and distributed by fax. For info, contact *Hepp News* (tel: 401-863-1725; email: brunap@brown.edu).

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Spectra
The quarterly newsletter of the Swiss Federal Office of Public Health. Regularly carries updates on the many innovative approaches to HIV prevention in prison implemented in Switzerland (such as needle distribution programs). Trilingual (German, English, French). For a free subscription, contact GEWA, Tannholzstrasse 14, PO Box, CH-3052 Zollikofen.

Websites

www.aidslaw.ca
The website of the Canadian HIV/AIDS Legal Network. Nowhere will you find more info on HIV/AIDS in prisons than on this site.

www.catie.ca
The Community AIDS Treatment Information Exchange website, an essential source for treatment information.

For More Resources ...

consult ***Legal and Ethical Issues Raised by HIV/AIDS: Literature Review and Annotated Bibliography*. Montréal: Canadian HIV/AIDS Legal Network, 2nd edition, 1998.** Contains a section on HIV/AIDS in prisons with many additional resources. The web version, available at <www.aidslaw.ca/biblio/c-20.htm>, is bilingual (English and French) and updated regularly.

Copies of the info sheets are available on the Network website at www.aidslaw.ca and through the Canadian HIV/AIDS Clearinghouse (tel: 613 725-3434; email: aids/sida@cpha.ca). For further information, contact the Network (tel: 514 397-6828; fax: 514 397-8570; email: info@aidslaw.ca).

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Prevention of Sexually Transmitted and Bloodborne Diseases in Prisons: The Experience of the Québec Detention Centre

The provincial detention centre in Québec City has had an innovative STD prevention project since 1993, involving a partnership between prison authorities, public health, and a community-based organization serving the needs of drug users. The following article summarizes the main results of the recent evaluation of the project.

History

In 1990 the Québec detention centre (CDQ) participated in a committee for the prevention of sexually transmitted and bloodborne diseases (STBDs) in collaboration with the Québec public health centre (CSPQ). The committee's activities and, subsequently, the direction the project took in prisons, was based on the principle of the involvement of the various partners in prevention work. The strategies chosen were the creation of a cross-sectoral committee and the support and training of correctional personnel by CSPQ professionals and physicians. There were activities well before the implementation of the intervention project in prisons. The STBDs in prisons program, which officially began in the fall of 1993, was ratified by a study committee. Three partners – the CDQ, the CSPQ, and Point de Repères (a community organization involved in STBD prevention among injection drug users) participated in its implementation. The CDQ, under the authority of Québec's Ministry of public security, admits people whose maximum sentence is two years less a day. It can admit up to 500 male inmates and 40 female inmates. Most of the inmates are between 20 and 30 years of age. During 1993, there were more than 9000 admissions of males and more than 1000 admissions of females recorded. The CDQ employs some 300 correctional officers.

Evaluation

An evaluation of the intervention project was carried out based on various data sources that made it possible to follow the program's development and to collect the opinions of those working in the prison and those incarcerated after the program was implemented. The evaluation report takes three aspects into account: the implementation of the program, conditions for success, and the feasibility of making such a project permanent.

Implementation

Implementation of the program was based in large part on the participation of CDQ personnel, who were responsible for creating conditions that ensured its being carried out. For example, management had to support the prevention activities for prisoners by providing a consultation office for the STBD worker; by participating in project monitoring; by providing easy and equitable access to condoms and

bleach for prisoners; by establishing non-nominal HIV testing; by respecting the confidentiality of the STBD worker's interventions; and by encouraging collaborative relations with the health service and the other professionals on the inside. The cooperation of correctional officers and consultants who were experts on the prison environment was also essential to the project's proper functioning.

With regard to how activities to promote preventive behaviours with respect to STBDs are accepted and carried out, the main obstacles are linked to the apparent contradiction between prevention messages and disciplinary measures. Certain protective measures can be introduced more easily into daily prison life, such as access to bleach, whereas others, such as access to condoms and syringes during incarceration, are controversial.

With respect to the dissemination of prevention messages to inmates, the use of audiovisual aids has proved worthwhile and effective in reaching and capturing inmates' interest. A large number of inmates do not read much, and resorting to written messages seems likely to be less effective in reaching these people. Consequently, the comic strip *Tête à queue* was an out-and-out success because of its format and the language used.

Individual meetings are the cornerstone of the intervention program in prisons because they encourage discussion of subjects that are generally taboo in such environments. Group encounters proved more difficult to organize and maintain because of the many activities offered to inmates. These activities are important because, due to them, greater numbers of people can be made aware of the issues.

Conditions for success

In the development of the intervention program, it was necessary to take into account the functioning of the host correctional establishment. The ambiguity of the relation between the regulations and the protection measures made the correctional staff uncomfortable when the time came to apply the program's directives. Reluctance to distribute or to make condoms, bleach, and syringes accessible in an environment where sexual relations and drug use are subject to disciplinary measures is one foreseeable reaction. To forestall this, those responsible for the project opted to install condom dispensing machines in places where inmates circulate and to make undiluted bleach available in locations under minimal surveillance.

The confidentiality of interventions was also mentioned during interviews with correctional staff, who recognize the importance of having an external resource not under the authority of the detention centre. This delinking of the proponent of the STBD-prevention activities and the front-line personnel responsible for enforcing the detention centre's regulations made it possible to reduce correctional staff discomfort with respect to the application of measures to prevent the spread of STBDs.

The security rules of the host detention centre are also a factor that will have an impact on the development of a prevention program. For example, the rules governing inmate movement within the detention centre cannot be suddenly abolished simply because someone has decided to implement a prevention program. The time it takes to adapt will vary depending on the flexibility of the rules in question.

Two other measures proved to be significant in the development of the project and in its integration into the establishment's operations: the creation of a decision-making structure and the integration of the STBD program into ongoing programs at the CDQ. Thus, the formation of a decision-making committee on the implementation of the project, made up of the three partners involved in the program, made it possible to regularly take stock of how the program was functioning because it allowed for ideas to be exchanged and disagreements to be expressed. Although some aspects of the intervention program have been delayed or hindered because of resistance from certain persons, this way of operating has proved effective for the implementation of the project.

Among the conditions for success, the promotion of awareness among those involved in the correctional environment is important to their coming to accept the project. This kind of activity involves both the issue of STBDs themselves and the role of the STBD worker. If correctional staff don't perceive the risks and if they don't properly understand the STBD-prevention worker's role, it will be more difficult for them to accept that person's presence among them. The STBD worker should take the time to understand the correctional staff's dynamic and work climate and try to create bonds of trust with its members.

How to make the project permanent

The program was perceived by correctional staff as an agent of change. Had they known this information from the outset, the initial design of the project would have changed in order to take into account the needs of staff during the first year of implementation and to provide for front-line staff being prepared to gradually take over certain activities. With respect to the usefulness of the program for correctional services officers, the demystification of AIDS, the support of those involved in the correctional environment, and the reducing of their work load may be noted. The presence of non-CDQ personnel favoured the creation of a

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neutral zone, useful for both inmates and correctional staff. Moreover, the fact that the program was designed in connection with a non-CDQ resource ensured continuity in the intervention program, and this was perceived positively by correctional staff.

The involvement of correctional staff in taking charge of certain program activities should be seriously considered. The willingness to become involved should not be understood as simply a transfer of tasks. Correctional service officers have an important role to play in preventing STBDs; they have indicated the key areas in which they feel competent to intervene and the way in which they perceive their involvement. Being involved in prevention is also, for correctional staff, a way of taking ownership of the program, of interpreting it according to the reintegration objectives they are pursuing with the inmates. However, one should avoid putting those involved in uncomfortable situations; their training needs with regard to STBDs should be considered. Nevertheless, this is not a question of transferring activities from the STBD-prevention worker to correctional officers, but rather of developing linkages so that each person can feel they are a stakeholder in the process of program implementation.

– Lina Noël

Lina Noël is a research officer at the Centre de santé public du Québec. She was responsible for evaluating the "Prevention of Sexually Transmitted and Bloodborne Diseases in Prisons" project. She can be reached at the Centre de santé publique du Québec, 2400 d'Estimauville, Beauport QC G1E 7G9, Canada or by email at <lnoel@cspq.qc.ca>. For a complete copy of the 136-page evaluation report, entitled *Prévention des maladies trasmissibles sexuellement et par le sang en milieu carcéral – L'expérience du Centre de Détention du Québec*, send a cheque for $20 payable to the order of CHUQ, Pavillon CHUL, with a note to Ms Chantal Garneau, Équipe des maladies infectieuses, Centre de santé publique du Québec, to the same address as for Ms Noël.

PUBLICATIONS REVIEWED

Harm Reduction: A New Direction for Drug Policies and Programs[1]

This collection of selected, revised papers originally presented at the Fifth International Conference on the Reduction of Drug-Related Harm, held in Toronto, Canada, 6-10 March 1994, continues the "journey towards a new paradigm," to new ways of understanding and reducing drug-related harm. Both guidebook and travel journal, *Harm Reduction: A New Direction for Drug Policies and Programs* makes a compelling case for the necessity of a new direction, while in its 476 pages it illuminates the complexity of the journey to be taken.

"[T]he search for a harm reduction perspective was a reaction to deficiencies of existing approaches" (at 4), as the editors make clear in their Introduction, and they go on to summarize the flaws of the prohibitionist, legalization, and medical models of dealing with drug-related harm. Though cursory, this summary provides a necessary background to understanding the genesis of harm reduction, born of the "need for more pragmatic strategies for minimizing the risk of HIV transmission among injection drug users ... [and] the success of certain pragmatic and innovative risk reduction programs ... such as syringe-exchange schemes and prescribing of 'hard' drugs." (at 3)

How far the international harm-reduction movement has come is evident in the breadth of issues and settings encompassed in this book. As the third in a series of volumes based on the international harm-reduction conferences, the editors note how each volume has marked a developmental stage in harm reduction's growth "beyond the confines of prevention of HIV infection among injection drug users." (at 10) Thus, there are sections devoted to Human Rights; Alcohol and Public Health; and History, Policy and Social Theory. Contributors discuss policy, programs, and research, with a majority of the 26 articles being drawn from North America (16) and Europe (5). There is an emphasis on particular issues facing women, but only one article deals with harm-reduction work with people of colour, reporting on work done with the Punjabi community in Ontario. Several chapters focus on young people and one reports on a harm-reduction program with older adults.

There is an overwhelming concentration on harm reduction as it relates to drug consumption, and drugs given a particular focus are cocaine, heroin, and ecstasy (MDMA). However, two pieces look at harm reduction and drug production, in the case of coca farmers in Colombia and home production of heroin in Australia.

In presenting this heterogeneous mix of practice and experience, the editors highlight a central quality of the international harm-reduction movement – its inclusivity. Freeing itself from moral, legal, or medical interpretations of the phenomenon of drug use allows harm reduction to embrace "quite eclectically ... [a]ny strategy that helps to achieve the immediate and realizable goal of reduction of harmful consequences of drug use." (at 8) But in the absence of some key questions being addressed, the simplicity of this statement becomes disingenuous. What is meant by harm? Who should define what is meant by harm? Harmful consequences for whom? Inclusivity becomes meaningless if, as the editors warn at the end of their Introduction, harm reduction risks becoming "all things to all people." (at 11) What sense can be made of a term that is embargoed by US drug research agencies and the United Nations Drug Control Program because they believe it promotes drug use and undermines the War on Drugs, as noted by Ernest Drucker in his Foreword, while it is embraced by the 28th World Health Organization Expert Committee on Drug Dependence because they believe it includes strategies to regulate drug supply, as reported by Robin Room in Chapter 7?

Sensing readers' possible confusion, the editors offer a summary of common themes they tell us have emerged from "extensive discussion." (at 7) Twelve such themes are grouped under three headings (conceptual, practical, and policy) and they offer a grip on the meaning of harm reduction, especially for those readers coming to this field for the first time. A common thread within the three categories is the importance of the drug user: thus, "the user is regarded as an active rather than passive entity" (conceptual); "Harm reduction programs solicit the cooperation and participation of drug users in determining the most appropriate prevention or intervention modalities" (practical); and, implicitly, in harm reduction's focus on human rights (policy) and users' rights to be involved in determining the services provided for them.

This thread links several of the contributions to the volume. In presenting an alternative approach to AIDS outreach and prevention for street youth in New York City (Chapter 23), Clatt et al reaffirm that harm reduction is based on "the recognition that particular behavioral goals must be tailored to the specific needs and real-life capacities" (at 404) of individual users, "that we cannot know ... until we are prepared to listen." (at 406) A similar point, about the importance of the relationship between providers and users of harm-reduction services, is made by Crosby in her account of the work of Manchester Action on Street Health (MASH) with street prostitutes (Chapter 24). Recognizing that "prevention of HIV infection is not a particularly high priority in [clients'] daily lives," (at 415) MASH staff respond to clients' immediate concerns at times and in places that are most convenient for the client group. "The trust established by this approach enables staff to make more focused interventions at a later stage without having alienated clients." (at 415)

The thread of user involvement begins to fray somewhat in the chapters on alcohol and harm reduction, however. Single's description of A Harm Reduction Approach to Alcohol-Problem Prevention (Chapter 11) echoes the editors' thematic emphasis on the harmful consequences of substance use, rather than use per se, but is silent on the process whereby these consequences are identified and the participation of alcohol users in such a process. Indeed, the examples of harm reduction he offers are, for the most part, policy measures decided "from above," like air bags in cars and the promotion of low-alcohol beverages. Marlatt and Baer's piece on Harm Reduction and Alcohol Abuse (Chapter 15), describing research and interventions among college students in the US, defines the goal of harm reduction as "being to move the individual with alcohol problems along this continuum [of] ... harmful consequences," (at 258) which sounds suspiciously like treating the service user as a passive rather than active entity. More distressing, from the editors' point of view, is Marlatt and Baer's ensuing statement that it is "important that the harm reduction model accepts abstinence as the ideal or ultimate risk-reduction goal," (at 258) in striking contrast to the Introduction's stress on "the irrelevance of abstinence" (at 8) as a key theme of harm reduction.

Healthy disagreement? The editors' recourse to organic metaphors to explain divergent opinions about harm reduction is instructive, telling

us that they believe such disagreements to be a part of harm reduction's inevitable maturation, as a "nascent" perspective, "developing, rather than ... fully developed." Arguments over its meaning and philosophy are characterized as a part of harm reduction's growing pains, although the editors urge that it is vital to "move towards a common understanding and application in the future." (at 11) At times, the editors' terminology suggests that they wish they were in that future now, slipping from the modesty of the term "harm reduction perspective" to the imposingly capitalized Harm Reduction Model, perhaps hoping that these upper case letters will confer that missing sense of coherence.

On the other hand, perhaps it is not a sense of coherence that is missing from this volume, but a sense of contest. For the question implicitly raised by the competing meanings of harm reduction presented in the book, although never explicitly addressed, is: Whose meanings count? Who are the experts in harm reduction? This is the question prompted, if not phrased, by the themes of user agency and user-determined services outlined in the editors' Introduction. In calling for a "genuine respect for the lives and abilities of users and a recognition of their critical role in harm reduction," (at 304) Sorge and Harlow (Chapter 18) argue persuasively that New York State's approach to needle exchange is seriously compromised by anti-user bias, notably in its dual prohibitions on secondary distribution of injection equipment (that is, from a service user to another injector, whether or not they are enrolled in a program) and on handling injection equipment by active users who are also exchange staff or volunteers. Such prohibitions spring from the particular context of US drug policy (the "War on Drugs") and its demonization of drug users as unworthy of respect and responsibility. However, it illustrates, albeit in extreme form, how deep-seated the notion of drug user incapacity is and the need to challenge the privileging of professional expertise over the expertise of users' experience.

A striking similarity across national boundaries is the confusion that characterizes drug policy-making.

Users' voices are scarcely to be heard in the volume. Chapter 25 is entitled A Harm Reduction Approach to Treating Older Adults: The Clients Speak, but it is in fact the researchers speaking, drawing on their case-study interviews with older adults to evaluate the Lifestyle Enrichment for Senior Adults program in Ottawa, Canada. There are evident constraints on the expression of users' voices in this book – eg, the illegal nature of much substance use and the public nature of the forum from which the contributions are drawn. But the absence of such voices returns us to the issue of contested meanings. The editors emphasize harm reduction's evolution through dialogue without reflecting on the struggle that users of services (and, to a lesser extent, users of illegal drugs) face in making themselves heard on their own terms within this dialogue. Little if anything is said about users' experience of organizing to express a collective voice, despite a lengthy history and recent proliferation of such efforts.

This struggle for voice is about power – the power that is exercised to name deviance, diagnose pathology, and separate expertise from experience. Drug users' exclusion from this power over their lives is evident in Rosenbaum's history of methadone policies and programs (Chapter 4), which charts the history of methadone maintenance from being "the original form of drug harm reduction in the United States" (at 69) to being a form of "containment of addicts," (at 73) a history in which "[m]ethadone users have been victims of the political and social manoeuvring of the last twenty years." This volume's strongest section, on History, Policy and Social Theory, provides fascinating insights into the nature and consequences of this "manoeuvring" in different societies.

A striking similarity across national boundaries is the confusion that characterizes drug policy-making. Fischer's detailed account of The Battle for a New Canadian Drug Law (Chapter 3) is illustrative of the politicking around drugs and the bizarre thinking that may result. He quotes one Liberal MP as saying that "this new law will put Canada in the forefront ... of leading the War on Drugs from a perspective of harm reduction." That the War on Drugs could be led by the harm-reduction perspective will be news to most, perhaps all, harm-reduction practitioners. But they will be less surprised to read Cohen's historical description of two Dutch drug-policy commissions (Chapter 1), which established the co-existence of harm

reduction with criminal justice supply-reduction efforts by distinguishing between reducing the harm of an individual's consumption and suppressing drug production and trafficking. That such co-existence could be contradictory Cohen illustrates in the case of ecstasy; while the state sponsors quality checks on ecstasy at raves for users' benefit, the state also attempts to eradicate large-scale production of ecstasy, thus driving its production "underground" and increasing the likelihood of an adulterated product.

The ability of harm-reduction efforts to co-exist with a "counterproductive punitive policy" is celebrated by the editors as evidence of its pragmatic nature, which by working within the dominant system of legal sanction can help to bring about gradual policy change. But such Trojan-horse pragmatism is open to question, not least in this volume's own welcome emphasis on human rights. The denial of harm-reduction programs to drug-using prisoners in nearly every penal system in the world, well documented by Jürgens in Chapter 9, inevitably places harm-reduction advocates in an oppositional stance with respect to prevailing penal policy. Noble's disturbing account (Chapter 10) of the use of prenatal drug testing on women and their coerced drug treatment in the name of child-abuse prevention is a further example of infringement of basic human rights incompatible with harm-reduction principles.

The book's discussion of human rights implicitly challenges those working within harm reduction to consider not only the extent of their contradictory co-existence with dominant and oppressive practices and policies, but also the ways in which they can articulate their opposition. As Arganaras reminds us in his description of the harmful effects of counter-narcotics policies in Colombia (Chapter 6), such an articulated opposition requires the voices of those most directly affected, in this case the peasants in the coca-growing regions. The volume's single Latin American contribution also emphasizes that harm reduction in the Colombian context is necessarily an oppositional response to the geopolitical imperatives of the US War on Drugs, the influence of which is being felt in an increasing number of countries, especially in Latin America and Asia. It is to be hoped that forthcoming volumes will address this influence, and these parts of the world, in more depth.

The utility of drugs to those in power to marginalize and stigmatize threats to the social order has evidently helped to sustain race, gender and class hierarchies. Thus, the search for harm reduction is not only a search for policies and programs but also a search for a politics that understands the multiple ways in which drugs are used, by individuals and the State, and the harms that result.

What is clear from the above is that the "social and political manoeuvring" that has surrounded drug policy has caused a great deal of harm. For some, like Beauchesne in Chapter 2, the answer lies in drug legalization, and she discusses the issues and questions arising from an attempt to remove the harms caused by drug prohibition. Others in the harm-reduction movement, especially in the US, prefer not to be embroiled in the polarized legalization debate but would probably agree with Beauchesne that there is a need to take "the role of drug use in post-industrial society into account." (at 42) While questioning the boundaries between legal and illegal drugs, there is another sense in which the use of drugs must be considered, and that is the ways that "drugs" as an issue is used to preserve relationships of power within societies. The dearth of contributions by or about people of colour limits this volume's ability to illuminate such functions, but the utility of drugs to those in power to marginalize and stigmatize threats to the social order has evidently helped to sustain race, gender, and class hierarchies. Thus, the search for harm reduction is not only a search for policies and programs but also a search for a politics that understands the multiple ways in which drugs are used, by individuals and the state, and the harms that result. Without this political sensibility, the "new direction" promised by the book's title risks being dangerously off course.

– reviewed by Alan Greig

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[1] PG Erickson, DM Riley, YW Cheung, PA O'Hare. *Harm Reduction: A New Direction for Drug Policies and Programs*. Toronto: University of Toronto Press, 1997. 476 pp, ISBN 0-8020-0756-2 (cloth), ISBN 0-8020-7805-2 (paper).

NEW PUBLICATIONS

HIV/AIDS and Human Rights: Stories from the Frontlines[1]

People working on the frontlines of the HIV/AIDS epidemic tell their own human rights stories in a new publication released by the International Council of AIDS Service Organizations (ICASO).

Stories from the Frontlines recounts how community-based organizations have responded to human rights violations and how they have mounted campaigns to promote and protect human rights in the context of HIV/AIDS. Many of the articles are success stories illustrating important lessons learned. They were written by people and organizations working on the frontlines of the epidemic.

Stories from the Frontlines describes how community-based organizations have improved access to treatments for people with HIV/AIDS by fighting in the courts, lobbying politicians, using the media, organizing public actions, and setting up distribution pipelines. *Stories* tells how similar strategies were used to reduce the number of deportations of immigrants living with HIV/AIDS in France and to get a new AIDS law adopted in the Philippines; how education was instrumental in getting residents of Quito, Ecuador to accept a new AIDS hostel in their neighbourhood; and how using the court system has been a cornerstone of the human rights response to HIV/AIDS in India.

Other articles deal with responses to violations in the areas of employment, confidentiality, marriage, prisons, violence, and access to care. *Stories* also provides examples of recent human rights abuses and issues that need to be addressed.

Stories from the Frontlines is available in English, French, and Spanish. The publication can be downloaded directly from the ICASO website at <http://www.icaso.org>. Copies can also be obtained from any of the five ICASO regional secretariats or from the Central Secretariat. To obtain contact information for the regional secretariats, check the website. The contact information for the Central Secretariat is as follows: ICASO – Central Secretariat, 399 Church Street, 4th Floor, Toronto, ON, Canada M5B 2J6. Contact: Yolanta Cwik (tel: 416 340-8484 ext 221; fax: 416 340-8224; email: <yolantac@icaso.org>.

[1] International Council of AIDS Service Organizations. *HIV/AIDS and Human Rights: Stories from the Frontlines*. Toronto: ICASO, 1999 (25 pp).

UNAIDS Statement on Drug Use and HIV/AIDS

The Joint United Nations Programme on HIV/AIDS (UNAIDS) recently published its statement on drug use and HIV/AIDS, presented at the United Nations General Assembly Special Session on Drugs held in New York on 9 June 1998. Significantly, the statement endorses a harm-reduction approach to drug use.[1]

It explains the connection between drug use and HIV/AIDS, pointing out that in some parts of the world "injection drug use has helped kick-start the HIV epidemic" and that in the world today

> there are at least 5.5 million – and possibly up to 10 million – injection drug users, ranging across 128 countries and territories – up from 80 six years ago. Some 700 000 people in the United States alone currently inject. In the Russian Federation, there are estimated to be between 350 000 and 700 000 injection drug users – a figure over 20 times higher than the estimate in 1990.[2]

Given that HIV infection is one of the most serious possible consequences of injecting drugs, according to UNAIDS "our approach must be

to reduce the harm to individuals and communities – by advocating for and strengthening effective HIV prevention programmes among drug users."[3]

The statement emphasizes the importance of early intervention, while HIV prevalence is still low, and of putting in place a comprehensive package of measures to prevent the spread of HIV, including provision of sterile injection equipment, raising awareness among and educating injectors and their partners about HIV risks and safe practices, making drug treatment programs available, etc. It says:

> No single element of this package will be effective if practised on its own. But by far the most important element is to provide sterile injecting equipment to injectors.[4]

Beyond the specific essential components mentioned above, the statement mentions another important requirement:

> This requirement is to ensure a supportive environment. This means reducing poverty and creating opportunities for education and employment – the lack of which often leads people, out of sheer despair, to inject drugs.[5]

The statement concludes by providing some examples of harm-reduction programs that work, and cites the example of Australia, where extensive needle exchange programs, bleach distribution, access to methadone maintenance treatment, and comprehensive AIDS education have contributed to the low prevalence of HIV among injection drug users.

Copies of the statement can be obtained through UNAIDS (20 avenue Appia, 1211 Geneva 27, Switzerland; tel: 41-22 791-4651; fax: 41-22 791-4165; email: unaids@unaids.org) or downloaded from its website at <www.unaids.org>.

[1] UNAIDS. *Drug Use and HIV/AIDS. UNAIDS Statement Presented at the United Nations General Assembly Special Session on Drugs*. Geneva: UNAIDS Best Practice Collection Key Material, March 1999 (UNAIDS 99.1E, 9 pp).

[2] bid at 5-6.

[3] Ibid at 6.

[4] bid.

[5] Ibid at 7.

Background Paper on Compulsory Licensing and Parallel Importing[1]

In response to recent queries about the issue of compulsory licensing and parallel importing, the International Council of AIDS Service Organizations (ICASO) has prepared a background document for community groups and individuals interested in this topic.

Written by Margaret Duckett, the paper reviews two key questions:

- What does compulsory licensing mean; what does parallel importing mean?
- Will they improve access to essential drugs for people with HIV/AIDS?

Since 1998, treatment activists have increasingly been talking about the effect of international trade laws on access to essential drugs, especially HIV-related medications. Recently these issues have been the subject of considerable debate among treatment activists, pharmaceutical companies, governments, and academics. Two strategies in particular have been considered to bring down the price of drug therapies: parallel importing, which involves bringing drugs in from another country; and compulsory licensing, which involves using a legal intervention to restrict the monopoly rights of existing patent holders and make generic drugs more available.

The background paper aims to provide people with sufficient information to participate fully in the debate and to help people better understand the potential for advocacy work on these matters in their own countries and with their own governments.

The document has 10 sections:

1. an introduction
2. background to the issues
3. information on parallel importing
4. information on compulsory licensing
5. a section from the consumer's perspective
6. a section on commonly asked questions
7. other means of lowering drug prices
8. a section on future action
9. where to go for further information – other websites, listservs, and publications
10. a glossary of key terms

The background paper is available in English, French, and Spanish on the ICASO website at <http://www.icaso.org/compulsory.htm>.

[1] *Compulsory Licensing and Parallel Importing. What Do They Mean? Will They Improve Access to Essential Drugs for People Living with HIV/AIDS? Background Paper*. Toronto: ICASO, 1999.

Positive Change[1]

***Positive Change* is a manual of legal and practical information on issues of concern for people with HIV and AIDS in British Columbia, produced by the British Columbia Persons with AIDS Society (BCPWA) and funded and supported by the Society and the Law Foundation of British Columbia.**

The manual is intended as a resource for individuals and organizations working on behalf of people with HIV/AIDS. It contains sections on:

- "the skills of a good advocate" (highlights the importance of research, and provides tips on how to best advocate for clients);
- British Columbia benefits (explains the BC Benefits programs of the Ministry of Human Resources);
- Canada Pension Plan benefits (explains eligibility criteria, application procedures, and how to appeal denials of CPP entitlements, and examines the implications of returning to work for CPP disability pension recipients);
- Employment Insurance Benefits (for individuals considering leaving their jobs, examines the EI eligibility criteria, amounts of benefits, when to apply, and how to appeal denials of benefits);
- assistance with debts (describes the range of options, including debt forgiveness, interest relief, and bankruptcy);
- human rights (explains under what circumstances a complaint can be filed under the BC Human Rights Code and the Canadian Human Rights Act, and describes the complaint process);
- confidentiality and HIV/AIDS (covers confidentiality matters relating to HIV testing, tenancy, schools, government services, and private insurance companies); and
- wills, living wills, and power of attorney (explains how to prepare, execute and cancel wills, living wills, health-care directives, and power of attorney).

A must-read for all doing advocacy work for people with HIV/AIDS, not only in British Columbia, but across Canada.

For a copy of *Positive Change*, contact BCPWA at 604 893-2223 or <bcpwa@parc.org>.

[1] *Positive Change: Advocacy for People with HIV Disease and AIDS*. Vancouver: Law Foundation of British Columbia, February 1999.

AIDS in the Workplace, Let's Do Something about It, and How![1]

This is the third, revised edition of a guide on AIDS in the workplace, written to respond to the needs of employers, employees, and unions.

The guide contains up-to-date information about HIV/AIDS and about how HIV is (and is not) transmitted; the prevalence of HIV in Québec and worldwide; and about AIDS in the workplace, and the law. In particular, it addresses questions such as: Are job applicants or employees who are HIV-positive required to inform their employers? Can individuals be forced to undergo HIV testing before being hired or during the course of their employment? How should one react if employees refuse to work with an HIV-positive co-worker? Do employers have the right to consult companies' medical records if they think that an employee is HIV-positive? Can an HIV-positive employee be excluded from a group insurance plan? Considering the prescription drug insurance program in Québec, is an employer now entitled to know if an employee or a member of the employee's family is HIV-positive?

The guide then discusses the benefits for employers of implementing an AIDS action plan, and suggests procedures for implementing such a plan. It also explains how an HIV/AIDS policy can be developed, and states that it

> should be based on the following principles recognized by international organizations such as the International Labour Office, the World Health Organization and the European Union and applied by many governments and businesses in both the public and private sector:
>
> 1. HIV positive people have the same basic rights and freedoms as all other individuals, namely the right to inviolability as individuals, dignity, respect of privacy and professional privilege.

They must not be subjected to harassment or discrimination.

2. Scientific and epidemiological research shows that there is absolutely no risk of individuals with AIDS or who are HIV-positive transmitting HIV to their colleagues during regular contact at the workplace.
3. Individuals with HIV and AIDS have the right to work. If they are unable to perform job tasks as a result of their condition, they have the right to the same sick leave and fringe benefits as an employee with another illness. They are also entitled to return to their job once their condition allows them to.
4. The employer must not exhibit nor tolerate any form of discrimination or harassment in the workplace towards an individual who is HIV-positive, either during hiring, in the course of employment or in terms of relations between personnel and customers.
5. Company and union leaders should develop, circulate and implement a non-discriminatory policy and AIDS program which should be presented in terms which are simple, clear and unambiguous.
6. Company and union leaders should, with the help of public health organizations, commit to informing personnel about HIV and the ways it is transmitted.
7. The employer cannot ask an applicant or an employee for medical or personal information or ask them to be tested for HIV.

   The only exceptions arise if the test is required by a country where the employee has agreed to work, or if the health and safety of others is threatened as a result of the employee being HIV-positive.

   Finally, an employee can agree to HIV testing after being accidentally exposed to body fluids or blood, and then only after attending counselling from a qualified person of their choice. In all cases, the test must be carried out with the informed consent of the employee.
8. The employer must ensure the confidentiality of information about employees, including medical information, by taking the necessary steps. All information in the medical records must be kept under the supervision of the health professional. This person, in accordance with their code of ethics, cannot divulge any information relating to a medical diagnosis. Only information about the employee's ability to work may be given to the employer.
9. In a workplace where there is a particular risk of exposure to HIV (health services, for example, where workers can come into contact with blood), the employer must offer education and training programs and provide the material necessary for implementing infection control measures. The employer must also make sure these measures are respected.[2]

The guide also contains strategies for circulating information about HIV/AIDS in the workplace, as well as information about further resources that could be useful to employers and employees.

Although written for Québec workplaces, most sections of this document will be extremely useful for employers, employees, and unions in other parts of Canada and internationally.

The guide is available, in French and English, from the "Programme sida en milieu de travail" in Montréal (tel: 514 282-1015) and on the website of the Québec Ministry of Health and Social Services at <www.msss.gouv.qc.ca>.

Selected additional readings:

AIDS and Your Workplace: Evolving Issues and Court Cases. Horsham, PA: LRP Publications, 1996 (66 pp). Explains some of the rulings in the United States on employment discrimination, access to health-care benefits, HIV exposure in the workplace, and workers' compensation. Materials are drawn from court cases and news stories that appeared in *AIDS Policy & Law*. For information, contact LRP Publications, Horsham, PA. Tel: 215 784-0860. Website (ordering info only): <www.lrp.com>. Price: US$21.50 plus shipping.

HIV/AIDS: What's Cooking Legally in the Food Service Industry. Horsham, PA: LRP Publications, 1999 (70 pp). A more recent US publication, focusing on employment issues in the food-service and hospitality industries. Discusses the latest developments in US law, the stigma of AIDS, legal obligations of employers, and questions such as: Can an employer ask about HIV? It also provides practical tips for accommodating workers with HIV, and includes a resource guide with additional information. Much of the material is drawn from issues of *AIDS Policy & Law*. For information, contact LRP Publications, Horsham, PA. Tel: 215 784-0860. Website (ordering info only): <www.lrp.com>.

HIV/AIDS Workplace Toolkit. The [US] Society for Human Resources Management (SHRM) provides this kit in electronic form to provide employers with an objective source of information on how to develop an HIV/AIDS workplace policy, using practical tips and hypothetical scenarios to provide insight for managers. The kit was developed jointly by SHRM and the National AIDS Fund. Website: <www.shrm.org/diversity/AIDSguide>.

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[1] *AIDS in the Workplace, Let's Do Something about It, and How!* Gouvernement du Québec, Ministère de la Santé et Services sociaux, 1999 (36 pp, ISBN 2-550-33996-7).

[2] Ibid at 23-24.

Quebecers' Attitudes toward HIV/AIDS[1]

This is a summary of the final report of an inquiry into attitudes and behaviours relating to HIV/AIDS among the general public in Québec, undertaken from 1995 to 1997.

The report consists of seven chapters: the first deals with Quebecers' attitudes toward people with HIV/AIDS and gay men; the second sketches a portrait of sexual activity among the heterosexual population; the third sets out indicators for sexual behaviours that risk transmitting HIV; the fourth examines the use of condoms by the general public; the fifth deals with behaviours adopted by Quebecers to protect themselves against sexually transmitted diseases and HIV; the sixth provides a sociodemographic and behavioural profile of two particular subgroups of respondents – sexual partners of injection drug users, and respondents who have already used drugs such as crack, cocaine, or heroin; and the last examines various aspects of HIV testing.

3501 Quebecers were interviewed for the study, which showed that, in general, Quebecers have positives attitudes toward people with HIV/AIDS. The youngest, the most educated, and those who know at least one person with HIV showed the most open attitudes. In the study, nearly one-third of participants knew a person with HIV/AIDS.

The study also showed that homophobia is significantly associated with less open attitudes toward people with HIV/AIDS. Women's attitude toward homosexuality is overall more positive than men's, with differences depending on age: young women are less homophobic than older women. People with the least education and those not born in Canada are the most homophobic.

Among the other noteworthy statistics to come out of the study, only 23.9 percent of respondents had ever had an HIV test.

The study concluded that, while attitudes toward people with HIV/AIDS in Québec are generally positive,

> efforts to make people aware and to fight against stigmatization, particularly among less educated groups, have to continue. The association between homophobia and negative attitudes toward people with HIV/AIDS shows that it is important to promote an attitude of tolerance toward homosexuality.[2]

For a copy of the report, which is available in French only, contact the Centre de documentation, Direction de la santé publique, 1301 Sherbrooke Street East, Montréal QC H2L 1M3, Canada. For more information about the study, Alix Adrien can be reached at <aadrien@santepub-mtl.qc.ca>.

[1] V Leaune, A Adrien. Les Québécois face au sida: Attitudes envers les personnes vivant avec le VIH et gestion des risques. Montréal: Direction de la santé publique, Régie régionale de la santé et des services sociaux de Montréal-Centre, December 1998.

[2] Ibid at 5.