AIDS & the Law - Opportunities & Limitations

Justice Michael Kirby

(Mr. Justice Michael Kirby is President. Court of Appeal, Supreme Court, Sydney, Australia. He is a former member of the World Health Organisation Global Commission on AIDS. The address - from which excerpts are printed here with permission - was delivered at the International Conference on Shaping the Future by Law, New Delhi, 22 March 1994.)

The courage of our convictions

For many the role of the law in the fight against HIV/AIDS is punitive. To ban conduct which might spread the virus. To isolate those who are already infected. To punish those who spread the virus and break the rules.

The issue presented by the dilemma of legal regulation in the context of HIV/AIDS is to find the strategy which best shapes a future society where the risks of HIV infection are minimised. It is essential to base responses upon a good empirical understanding of the target to which it is hoped the law will attach.

The most important point to be explored concerns the AIDS paradox. This teaches us that the most effective response to the epidemic is not prohibition or punishment but laws designed to truly affect human behaviour and thereby shape a society where the spread of AIDS is minimised.

In Australia the report commissioned for the State Government of New South Wales titled *Courage of our Convictions* seeks to identify the ways in which the State laws in Australia could be brought into harmony with the National HIV/AIDS Strategy. It recommends:

* decriminalisation ofbrothels;
* regulations and public health standards for sex workers;
* sex workers to be covered under the *Indusrial Relations Act;*
* privacy of HIV/AIDS patients and improvements in their redress against discrimination in the workplace;
* repeal laws making it an offense to administer drugs to oneselfand possession (of drugs);
* investigate the therapeutic use of marijuana as a prescribed treatment for HIV/AIDS and other terminal illnesses;
* abandon compulsory testing for HIV in prisons;
* promote the safety of prisoners by making condoms available to them;
* a *Natural Death Act* to permit terminally ill patients to 'die with dignity';
* distributing condoms to sexually active children;
* legal recognition of the status of permanent relationships between homosexual couples.

These proposals are by no means shocking to most Australians though a number of them have been criticised by their opponents within Australian society. It is the message of this paper that similar strategies will have to be addressed everywhere as the world confronts HIV/AIDS.

From Grandgor's distemper to HIV/AIDS

Five years after Columbus returned from his encounter with the New World, in the year 1497, there was an outbreak of disease, supposed to be venereal, in the city of Edinburgh, Scotland. The books of the Town Council record how quickly the disease progressed through Europe from its first report at the Siege of Naples two years earlier. The King of Scotland and his council terribly alarmed at this contagious distemper', issued a proclamation of the Sovereign Lord's will and command. The contagious sickness was named Grandgor. Those who had this plague were commanded to pass far out of the town to the island of Frith. If their bodies survived, they were obliged to take an unspecified cure. And everyone who did not comply with this command:

> *Falle be brynt on the cheik with the marking of Irne that thai may be kennit in tym to cum and thair-after if any of tham remanis that thai fall be banift."*

> (Shall be burnt on the cheek with the marking of iron that they may be known in time to come and thereafter if any of them remain that they shall be banished.)

Panic. Alarm. Banishment. Cruelty. Public stigmatisation. Law. These are the melancholy companions of disease and epidemics. The question for us is whether, in the five

hundred years since King James IV issued his Proclamation against Grandgor we have advanced in our appreciation of the limits and opportunities of law in the face of a public health crisis.

The basic rule and the AIDS paradox

So here stands our problem. In little more than a decade an extraordinary challenge to our species has struck the world. It has spread like wildfire. No continent is more at risk than over-populated Asia. We have photographed the virus that causes our affliction. We know the main modes of transmission. We have palliatives which will arrest some of its debilitating manifestations. But we have no cure.

Our only vaccine in these circumstances is knowledge. The only sure cure is prevention, by behaviour modification, of decisions made at moments immediately prior to sexual or drug-use activities.

Getting into the minds of people in such a way that they have the will to change their behaviour and reduce the risk of infection is not easy. But it is next to impossible unless the educational messages can be effectively spread. That will not happen if we do not win the confidence of the people most at risk. Such people include the young involved in sexual activity, homosexual and bisexual men, sex workers, unempowered women, spouses of men who

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This is a terrifying condition. There is no point mincing words. Like many of you I have sat at the bedside of precious friends. AIDS makes us angry.

But in law we must be rational. We must recognise the limitations of our discipline. We must acknowledge that law has only a partial success in achieving behaviour modification: particularly where sexual, drug-use or other human pleasures are involved. We must look for effective and just laws which slow the spread of AIDS.

I now want to assert a fundamental rule and a paradox.

Such laws must be based on a thorough understanding of the target. In the case of HIV/AIDS this requires a detailed knowledge of the virus and its mode of transmission. AIDS laws must not be based on ignorance, fear, political expediency and pandering to the demand of the citizenry for 'tough' measures. Good laws, like good ethics, will be founded in good data. One of the real dangers of AIDS is that it will produce a new virus - HIL - highly inefficient laws.

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are infected and injecting drug users. All of these groups have been the subject of centuries of prejudice and discriminatory laws. In their various ways they all feel alienated and remote from the messages of society.

The paradox is: if we are serious about the containment of the AIDS epidemic, we must enter their individual minds and get them to change behaviour which seems central to them to the definition of their being.

Australia, like India, is a federation. The strategy in Australia has been generally addressed towards containment. Even the single-minded policy against illegal drug use gave way to a national scheme for syringe exchange at local pharmacies. There is now widespread public and school education about HIV/AIDS. There is much more open discussion about sexuality and drug use. In most prisons, without change in prison regulations, condoms are discreetly provided and even cleaning bleach is left available to sterilise illicit syringes.

Legal responses to the epidemic

If human rights arguments are unpersuasive, it is much more likely that politicians and bureaucrats will come to appreciate the ineffectiveness and costs of laws imposing obligations of general or widespread screening. The screening can only be partly effective. Those in the 'window period' will slip through. False positives and

false negatives will give misleading results. Repeated testing will be necdcd. And thenthe problem would have to be faced as to what dould be done with people found positive. Even in Australia there would not be barbed wire enough. no institutions strong enough to contain all of the i nfcctcd.

Yet the infected arc in many cases highly productive to the economy. to themselves and their family for more than a decade. As such they are of no risk to their fellow citizens. Only certain intimate conduct is risky. AIDS is not contagious. The arguments for quarantine of HIV pat ien t s arc ihcrefore complet ely unpersuasive.

Laws and policies to do with AIDS must be efficient and cost-effective. Mass-screening - even screening of particular groups - is not an efficient strategy. If it does not lead to quarantine. it certainly does not lead to treat ment.

AIDS laws and strategies national and international must be achieved in conformity with international human rights norms. The right to life is primary and must be protected. But so must other rights: such as the right to privacy, the right to liberty and security, the right to freedom of movement, the right to marry and found a family, the right to work and to be educated and the right to freedom front inhuman or degrading treatment or punishment.

Criminal and public health law

Since exposure to HIV infection may lead to AIDS which is plainly life-threatening. it is the legitimate purpose of law to cndeavour to protect individuals. communities and nations front the spread of the virus.

The focus of the Australian proposals is upon high risk activities. It is not upon individuals and groups. It does not seek to stigmatise or reinforce prejudice against homo-scsuals, the promiscuous young. sex workers or drug-users.

In Victoria there is an innovative protocol. Where it is thought that a person with an infectious disease is likely to transmit it. there is the provision for the Head of the Health Department to require the person to be tested for HIV. If the test is positive the person may be ordered to undergo counselling where appropriate. Only if the counsclling is ineffective may the person's behaviour or movementsbe restrict cd.

Anti-discrimination law

It is impossible, by law. to prevent people having their own private prejudices and attitudes. Yet, as we have found in Australia. the law can have a supportive role in promoting education and informed attitudes based on fact, not prejudice. To eshibit prejudice because a person is sick. though that person presents no risk, is irrational and morally wrong. It adds to the heavy burden of illness.

Anti-discrimination laws can help to rectify such wrongs and to set the standards of proper social conduct. In many countries such as my own, such laws began with useful work on racial and religious prejudice. They then moved into prejudice on the ground of gender.

Now they are tackling other causes of prejudice such as age. handicap, disability and sesual orientation. There is a common enemy here. It is stereotyping.

Confidentiality

There have been a number of cases in Australia as in other countries where confidentiality of persons with HIV has been breached. It is imperative that confidentiality is assured in healthcare services, especially about a condition such as HIV/AIDS. If it is suspected that confidentiality cannot be assured, some people will not seek . services. Others will keep secret facts which should be revealed for good treatment.

In making decisions on issues concerning confidentiality, courts and other bodies must keep their eye on their utility to society as a whole and of preserving the general assurance of medical confidentiality. They should resist the breakdown of the duty of confidentiality, even in hard individual cases.

Conclusion - the big AIDS test

Yet the infected are in many cases highly productive to the economy, to themselves and their family for more than a decade. As such they are of no risk to their fellow citizens. Only certain intimate conduct is risky. AIDS is not contagious. The arguments for quarantine of HIV patients are therefore completely unpersuasive.

In the face of AIDS - this new, unheralded global crisis - we should all be humble. But we should be resolute. We should think of the many who this day will become infected and those who will learn of their infection. We should think of their families, parents, lovers, friends. We should spare thoughts for the healthworkers who will toil courageously over them - often with no drugs, always with no cure. Learning from past errors of cruel and inefficient laws we should resolve, this time, to do better. Stigma should have no dominion.

Hysterectomy in the mentally handicapped.

An abridged version of the statement issued by PARYAY.

(PARYAY is a group fostering hrrmane alternatives to hysterectomy in the mentally handicapped. Members can be contacted c/o Aalochana, 'Kedar', Kanchan Galli, Off Law College Road, Pune, 411 004, INDIA.)

We oppose the decision on hysterectomy in severely mentally retarded women in the asylum run by the government. The action was unjustified and unethical for the following reasons:

A. The operation was not medically indicated

1. Menstruation, even in the mentally handicapped, is not a disease to be eliminated. Hysterectomy has been carried out for the convenience of the caretaker institutions and not for the health of the mentally handicapped women. Would a 'normal' woman undergo this operation just to get rid of the 'trouble of menstruation', even after the completion of childbearing?

Since excreta from bowel and bladder need attention in the severely mentally handicapped, similar care can be provided for the outpourings of the uterus. How can hysterectomy be justified on the argument that it is the removal of a 'useless organ'? The utilitarian principle involved in advocating this operation has the sinister implication of justifying mercy killing of 'useless' people.

2. Hysterectomy is major surgery with a mortality rate of l-2 per 1000 operations and an even higher complication rate. **There is a widespread misconception, even among doctors that removal of the uterus, without removal of the ovaries has little or no long-term health consequences for the woman. This is not true.** 'Operative Gynaecology' by Telinde and a number of gynaecology books, state that 3-5 % of all women undergoing hysterectomy may need a second operation - the removal of their ovaries. Part of the blood supply to the ovaries is through the uterine artery. As this supply can be compromised by hysterectomy, ovarian function may be impaired. This results in the Residual Ovary Syndrome - a painful adnexal mass in the pelvis, general pelvic discomfort and pain during sexual intercourse. (We must not forget that one of the reasons for hysterectomy is to prevent pregnancies after forced intercourse).

3 Even if the ovaries are left in, their function often recedes after hysterectomy, lowering the levels of estrogen in the body. This may lead to cardiovascular disease and osteoporosis. Subjecting young girls to the operation therefore has severe and long term consequences. The fact that these operations are performed on healthy women compounds the risk.

4 Such hysterectomy is not recommended by any standard textbook of gynaecology or psychiatry. An extensive search through Medline and Popline shows that it is not an accepted practice in developed countries. Most of the literature discusses tubectomy and even this operation is approached