COMMENTARY: LEGAL AND POLICY IMPLICATIONS OF HIV TESTING

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The NZ AIDS Foundation grew out of the response of the gay community to the threat of AIDS in NZ, and remains the main channel for those most affected by AIDS and HIV to express their views, responses, and actions with regard to the epidemic. We support the conclusions of Mr Hodgson in his thorough examination of the legal and policy implications of HIV testing, but want to highlight some points, and to argue vigorously for a course of action that we believe is vital to the successful limitation of the epidemic.

In April 1989 there had been 126 cases of AIDS notified in NZ. There were seven cases in which the mechanics of transmission were not known, and three that were transmitted by medical misadventure (blood transfusion before screening was introduced). Of the rest 99% affected men who have sex with men. The pattern of reported HIV antibody tests reflects the same pattern.

Before considering further the role of testing and the law, it is important to know something about this population group that is so overwhelmingly affected by the epidemic. The demography of men who have sex with men is extremely limited: we still use Kinsey's studies of sexual behaviour in the 1940s and 50s, which suggested that approximately 10% of men predominantly homosexual, and that a further 20% engage in some sexual activity with other men at some time of their lives. Homosexuality has been socially disapproved, and legally punished in our society (although not in all human societies) for hundreds of years. It has been variously defined as a sin, a crime, and a mental disorder to recent times. It was removed from the American Psychiatric Association list of disorders in 1973 and from the WHO list in 1987. Until very recently, brutal "therapies" such as aversion therapy and shock treatment have been applied to people unfortunate enough to have sought "treatment". Although sexual acts were decriminalised in NZ in 1986, it remains perfectly legal to discriminate in terms of housing, employment, and to refuse goods, services, finance or care to any person on the grounds of their sexual orientation. Men who are homosexual learn to live with socially approved derogation and verbal abuse. Anti-gay violence and suicide are also hard to quantify, but the anecdotal evidence — if not the actual incidence — is increasing.

The consequences of personal rejection, social acrimony, legal discrimination, punishment, and violence are, not surprisingly, severe problems for the individual

in terms of self esteem, sense of social worth, ability to sustain long term social goals, and to trust those in authority. What should be surprising is the high level of individual achievement of many homosexual people, their extraordinary contribution to the professions — especially the caring professions, their ability to sustain a community, and their major commitment to the human rights of others.

So in formulating a public health response to the AIDS/HIV epidemic we believe that a fundamental dictum should be that which Justice Kirby first enunciated in 1986: "Given that the high risk groups are already accustomed to discrimination, alienation and isolation, the introduction of punitive measures, compulsory reporting and criminal offences may be seen as just the latest backlash of a prejudiced society."[1]

The traditional public health approach to an epidemic of an infectious disease is to identify those infected, to isolate them from those at risk, and to treat. Since it is the only one of the three that may be of any use in this epidemic, HIV antibody testing is obviously very important, and both Hodgson and Kirby have outlined fully the reasons why testing should remain voluntary and not coercive. But, in addition to the questions that Hodgson raises about the purpose of testing, we would wish to raise two others.

1 What will be done differently on the basis of the test result?
2 What are the consequences of the test for the individual being tested?

Hodgson's paper discusses the importance of counselling and education for prevention. We would emphasise that testing and counselling together have been demonstrated to be the most effective intervention for risk reduction that we have. Research in comparable countries (Australia, United States),[2] as well as in New Zealand, clearly supports the efficacy of individual counselling and testing in motivating and supporting behaviour change. It does not support testing on its own, nor is individual counselling alone sufficient to sustain behaviour change. Other prevention programmes geared to changing community norms about safe sex are necessary to sustain safer activity. The important point is that testing does not enable the doctor, or the health system, or the law, or anybody other than the patient, to do anything differently as the result of the test — only the individual tested is enabled to reduce his risk.

With regard to our second question, the major consequence to the individual is that,

1 Kirby, "AIDS legislation — turning up the heat?" (1986) 12 Journal of Medical Ethics, 187–194.
2 Coates et al, "Changes in sexual behaviour among gay and bisexual men since the beginning of the AIDS epidemic", Report to the US Congress Office of Technology, March 1988; Rosser, "Evaluation of the Efficacy of AIDS Education Interventions for Homosexually Active Men", unpublished PhD thesis, Flinders University of South Australia, 1989.

while it may contribute to his ability to reduce his risk of exposure to HIV, it also increases his risk of exposure to irrational fear, prejudice, and discrimination. The major factor that deters gay and bisexual men from testing is fear of discrimination on the basis of a positive test result. This discrimination may occur on the level of personal rejection by peers, family, and colleagues; or harassment; dismissal by employer, eviction by landlord, or refusal of care by health care workers. But it occurs most frequently from financial interests such as insurance companies.

In New Zealand this discrimination is perfectly legal and is currently flourishing. Without any mechanism to redress perceived wrongs, it is extraordinarily difficult to collect accurate information about them. And as long as there is no legal redress we will not be able to quantify the incidence, or describe accurately the way in which it occurs. But in those places where there is a mechanism, such as New York, sexual orientation discrimination forms a major part of the caseload. (In 1984–5 sexual orientation discrimination was the most common type of problem brought to the NY Human Rights Commission by the public — 32% of the total.) And in New Zealand gay community groups have begun to monitor discrimination in order to substantiate their call for legislation.

A most significant feature of AIDS-related discrimination — both here and overseas — is that it is frequently extremely difficult to separate from homophobia. Fear of AIDS has become indistinguishable from fear of the people seen to be most likely to carry it. This has been characterised as a three-fold pandemic: the silent epidemic of the virus, HIV; the obvious syndrome of illness called AIDS; and the third epidemic — the epidemic of fear. And it is important to recognise who has the most to fear — gay men. Gay men are threatened by our most intimate of relationships. It is our friends and lovers who are dying, and from whom any one of us may have been exposed to the virus before we even knew it existed. We also have to fear discrimination and violence — whether we remain at risk in our intimate behaviour or not.

A recent study of sexual attitudes and behaviour among men who have sex with men in Auckland[3] has identified some of the reasons why safer sex is so difficult to adopt and sustain for some men. These include low self esteem, fear of openly identifying as "gay", lack of clear sexual identity, difficulty in sustaining relationships. These difficulties are socially constructed — they are not inherent in the homosexual condition. If we are to contain this epidemic our society must examine what it does to homosexual men to produce such low self esteem, and such difficulty in sustaining relationships. Obviously one reason why gay men find it difficult to come to terms with sexual identity and to settle down in a mutually satisfying faithful monogamous

3 Chetwynd, Horn and Kelleher, "Safer sex among homosexual men: meaning and motivation", to be presented at V International AIDS Conference, Montreal, June 1989.

relationship is that they will be discriminated against if they do.
Furthermore, if we consider HIV testing, even the fact of having a test may result in discrimination: because by doing so we acknowledge that we may have been at risk. So the number of gay men who have taken an HIV test in Auckland, where there is no protection from discrimination, is only one third of those in Adelaide, where there is anti-discrimination legislation.

The NZ Government's record in response to AIDS is one of the most enlightened in the world — in terms of policy, funding, and the removal of legal obstacles. As both Kirby and Hodgson have pointed out, the role of law is limited, and certainly cannot provide any "quick fix". Any attempt to use co-ercive or punitive measures will fail. What we must do is make the world safe for those at risk to seek help, support, education, and fulfilling relationships. And the law can contribute to this in a major way by protecting the rights of those who are most vulnerable, and providing redress for those who are discriminated against unfairly.

In conclusion I should like to quote Dr Jonathan Mann, director of the World Health Organisation's Global Programme on AIDS: "In every society and every culture AIDS has led people inevitably to face a number of longstanding complex and pre-existing problems in the health and social systems. And we have to recognise the complexity of those problems, because those are some of the most intractably difficult and tragic issues."[4] And he has recently put this issue more bluntly: "If you have good education and services but the general social climate is discriminatory and stigmatising, then prevention just won't work."[5]

4 Mann, speech to first international meeting of AIDS Service Organisations, March 1989.
5 Mann,interview in V International AIDS Conference Bulletin, March 1989.