25 June 2003

Disability Discrimination Act Inquiry
Productivity Commission
Locked Bag 2, Collins Street East
MELBOURNE Vic 8003

Submission to DDA inquiry

Who am I?

I am a barrister in private practice at the Sydney bar. The bulk of my practice is in criminal law but I also practice in anti-discrimination, administrative and public health law.

As a gay man in a city which was and still is the epicentre of the HIV/AIDS epidemic in this country, I became involved in the community response in the early 1980s. I joined the board of the AIDS Council of NSW in 1986 and have been an elected member ever since. I was involved at the inception of the community sector's involvement in promoting a role for law and advocacy in Australia's response to the HIV/AIDS epidemic.

Since 1991, I have been involved in work overseas around HIV/AIDS law and policy, largely in the Asia-Pacific region. I keep abreast of developments and trends in relation to the epidemic around the world.

Focus of this submission

A proper focus of this Inquiry should be into improving the efficacy of the *Disability Discrimination Act* – ensuring that it better achieves its purposes. To that end, I heartily endorse the submission from the National Association of People Living With HIV/AIDS (NAPWA) and the Australian Federation of AIDS Organisations (AFAO) made in May 2003. I commend to you the paper *Barriers to access and effective use of anti-discrimination remedies for people living with HIV and HCV*.[1]

However, I have a particular interest in ensuring that the history of the *DDA* and its achievements are not overlooked. Some might think it peculiar that one could regard as appropriate a review of piece of human rights legislation

[1] <www.ancahrd.org/pubs/index.htm#papers>

by a body concerned with issues of productivity. I do not. As you will see from my submission below, I fall into the camp of those who think that the present state of the epidemic in Australia is, relative to the rest of the world, a public health success. Despite the losses in human life and the suffering, despite the costs, the fact remains that Australia has one of the most successful strategies for containment of the epidemic anywhere.

And one of the salient features of Australia's response to the HIV/AIDS epidemic has been pragmatism: 'will a proposed measure, designed to address some feature of the epidemic, actually WORK?'

The Australian HIV/AIDS strategy has been complex. Contributions to its achievements are made by a diverse range of people from many sectors of society, industry and government – in itself, a characteristic of an HIV/AIDS strategy which is recognised worldwide as best practice. In short, however, the *DDA* has contributed to reducing the stigma attached to HIV/AIDS and to empowering people with HIV, people otherwise affected and people at risk for HIV. It is that empowerment of vulnerable sub-populations, that 'normalisation' of disease – acceptance of public health responsibilities by everyone – which equips a nation to more effectively combat a public health threat like HIV/AIDS.

Background [2]

At the outset of the HIV/AIDS epidemic in this country, it was accepted by government that this public health threat was not going to be beaten without the active involvement of the affected communities. The community sector first advocated for recognition of the role for law and policy in the national HIV/AIDS strategy at the time of consultation around the green papers as to what Australia's policy response should be[3] and then in the drafting of the first of four *National HIV/AIDS Strategies*.[4] One product of research and consultation around the form which Australia's response should take was the seminal work on the legal response, *The Final Report of the Legal Working Party of the Intergovernmental Committee on AIDS*.[5]

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2 See J Ballard "Australia: Participation and Innovation in a Federal System" in D L Kirp & R Bayer (eds) *AIDS in the Industrialized Democracies* Rutgers UP, NJ, 1992; D Patterson "The Law" in E Timewell, V Minichiello & D Plummer (eds) *AIDS in Australia* Prentice Hall, Sydney, 1992.

3 *Australia's Response to AIDS* AGPS, Canberra, 1986; *AIDS: A Time to Care, A Time to Act*: *Towards a Strategy for Australians* AGPS, Canberra, 1988.

4 *National HIV/AIDS Strategy* AGPS, Canberra, 1989 – see in particular chapter 5.7.

5 Dept. Health, Housing & Community Services, Canberra, 1992. See now *Status Report: on implementation of the final report recommendations of the Legal Working Party* (June 1999) – accessible at <www.ancahrd.org/pubs/index.htm#papers> See also the Legal Working Party's discussion papers, especially the one on discrimination. See also *Report of the Privacy and HIV/AIDS Working Party* 1992. I can testify to the fact that, despite its relative

Partly as a result of the Legal Working Party's recommendations,[6] the Commonwealth government included in the *Disability Discrimination Act* – as enacted in 1992 – provisions intended to provide and which succeeded in achieving a uniform code around Australia for addressing discrimination on the ground of infection with a 'disease-causing organism'.[7] In itself, this has been a significant achievement and one which tends today to be overlooked.

Central themes to role of law in HIV/AIDS

Partly because of the infectious but not contagious modes of transmission of HIV (mainly injecting blood and penetrative sex), partly because of the stigma which attaches to them and partly because of the recognition[8] towards the end of the twentieth century of the contribution which human rights makes to better public health, a pro-human rights approach to the epidemic became national policy. This was a departure from the traditional public health model, formed in colonial times and which underpinned most public health legislation around the country – identification and isolation of the infected.

The new approach was described by Justice Michael Kirby, Australia's leading advocate for a rational response to the epidemic, as the "AIDS paradox" - paradoxically, the most effective way to promote behaviour modification essential to reduce transmission of HIV is not quarantine or punishment. It is protection of the vulnerable who are at risk and defence of their basic human rights. Only then will they be receptive to the messages and means necessary for self-protection and the protection of others.[9] That approach now underpins the acclaimed United Nations *HIV/AIDS and Human Rights International Guidelines*.[10]

The focus of efforts to fashion a legal response to HIV/AIDS which would best achieve the twins goals of Australia's national HIV/AIDS strategy – minimising infections and providing best possible care for those affected by HIV/AIDS – was reducing the stigma, or at least the effects of the stigma, which attached not just to people with HIV/AIDS but which also attached to people seen as at risk for HIV.

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antiquity, this *Final Report* of the Legal Working Party is still photocopied and used in other countries as a blueprint for a review of law and quasi-legal policy relating to HIV/AIDS.

6 See chapter 4 of the *Final Report*.

7 The issue in relation to this phrase was that people with HIV who had not progressed to symptomatic AIDS were suffering discrimination but were often seen by pre-1992 law as not disabled. This continues to vex disability discrimination law in the United States and contributes to the flawed response to the epidemic in that country.

8 Some would say, re-recognition.

9 See, eg, M J Kirby "AIDS and Human Rights" (1992) 1 *Australasian Gay & Lesbian Law Journal* 1; M J Kirby "AIDS and the Lawmaker: the Need for a Rigorous Approach and Realistic Goals" *Report of the Third National Conference on AIDS* AGPS, Canberra, 1988, pp.702-704.

10 <www.unaids.org/publications/documents/human/law/JC520-HumanRights-E.pdf> See also UNAIDS *Handbook for Legislators on HIV/AIDS, Law and Human Rights* Geneva, 1999 – authored by an Australian, Dr Helen Watchirs (ANU).

The role of stigma in the HIV/AIDS epidemic is well-documented.[11] The stigma extended (and still extends) as far as people who simply tried to find out whether they had HIV by undergoing testing for antibodies to the virus. For the first 15 years of the epidemic, medical facilities and health care workers were the primary sources of discrimination on the ground of HIV infection or perceived risk of infection.[12] It was important to stemming the rise of infections to create a climate where people with HIV and at risk for HIV could approach medical facilities and consult health care workers with confidence that their confidentiality and their integrity as citizens would be respected. Thus the two pillars of HIV/AIDS health care legal policy in this country became respecting confidentiality and protecting people from discrimination.

Although there were important precursors like the physical impairment provisions of the NSW *Anti-Discrimination Act 1977* and the Victorian *Equal Opportunity Act 1984*,[13] it was the *DDA* which provided the model for uniform protection against discrimination on the ground of infection with a disease.

Importance of role of protection against discrimination

Today, in Australia we take the tenets of confidentiality and protection from discrimination for granted. However, along with other factors, those tenets are responsible for an unusual epidemiological phenomenon – twenty-one years on, Australia's epidemic remains confined to the sub-population originally infected – sexually active gay men. And our injecting drug-user population still has very low levels of HIV infection.[14] In other countries, where the rights of people with HIV and at risk for HIV are not protected, the epidemic has spread into the general population and continues to increase. In other countries, more so than in Australia, people have reason to fear being identified as being infected with HIV.

How has Australia done this? By constructing and resourcing an environment which *enables* people at risk to takes measures to protect themselves and their partners. They are enabled to do so, in part, because of the legal assurances of at least some measure of protection from discrimination. As a result, we have achieved public health-oriented behaviour change on a level not before seen and in a very short time-frame.

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11 See, eg, documents at <www.unaids.org/humanrights/index.html> See also S Burris "Disease stigma in US public health law" *Jo. of Law, Medicine & Ethics*, 30(2002):179-190.

12 See, eg, *HIV/AIDS Related Discrimination: A submission to the NSW Anti-Discrimination* Board ACON, Sydney 1991; *Discrimination – The Other Epidemic* NSW Anti-Discrimination Board, Sydney, 1992; S Kippax, G Tillett, J Crawford & J Cregan *Discrimination in the Context of AIDS: Disease and Deviance* Dept. Human Services & Health, Canberra, 1992; HIV/*AIDS Related Discrimination: PLWHA Project Report*; *Research into HIV/AIDS Related Discrimination*; both, Dept. Human Services & Health, Canberra, 1994; E Herdman & S Kippax *Institutional Discrimination: Critical Ethnography of HIV/AIDS Related Discrimination in a Hospital Setting* National Centre in HIV Social Research, Sydney, 1995.

13 See chapter 4 of *Australian HIV/AIDS Legal Guide* 1st ed, Federation Press, Sydney, 1991.

14 For the figures, see National Centre in HIV Epidemiology and Clinical Research (NCHECR) *2002 HIV/AIDS, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report* Sydney, 2002; see also the latest *Australian HIV Surveillance Report* NCECHR, Sydney, January 2003 - <www.med.unsw.edu.au/nchecr/>

Given the clear link with improved health outcomes, it is not surprising that the legal aspects of Australia's response to HIV/AIDS has been a significant reason for Australia's HIV/AIDS strategy being hailed as a world leader.

There is a body of work on the economic costs of the HIV/AIDS epidemic.[15] These costs are incurred in loss of economically viable labour, training and social capital, and also in increases in health care costs, including hospital bed costs. In contributing to limiting the extent of the epidemic in Australia, the *DDA* has assisted in limiting the cost to this country of the epidemic. It has also contributed to the social capital generated by Australia's response to the epidemic. This social capital not only continues to address the epidemic in ways more effective than in most other countries but also is now paying off in many other different ways. Examples are the innovative intellectual base for addressing health care issues both here and abroad which Australia's AIDS Councils and HIV-related health care sector now comprise.

Conclusion

It is only human to become complacent and to tire of the efforts that need continually to be made to ensure that this public health threat is effectively addressed. And that work does need to continually be done. It is necessary also to understand that, in a country like Australia where people affected by and at risk of disease are enabled to take the steps necessary to look after themselves and each other, the ways in which this is done become more complex – risk is not so much prevented as managed. But for the affected communities and for the health care sector to continue to do this work which is of such inestimable benefit to the rest of the country the tools they are given need also to be refined and to be made more effective. They can become rather blunt over time. Thus the need for review and improving the *DDA* along the lines recommended in the NAPWA/AFAO submission.

In this way, the *DDA* will continue to be an important weapon in Australia's armoury of public health.

David Buchanan SC

PS I regret that I will be away from Australia until mid-August and thus unable to attend your public hearing in Sydney.

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15 See, eg, <www.unaids.org/publications/documents/economics/index.html>