International HIV/AIDS Policy Information Kit, Background and Critique

NB: This was written in June 1998 for an International HIV/AIDS Policy Information Kit, but discarded in favour of a less critical view. JA Ballard -

john.ballard@anu.edu.au

JA Ballard 1988

Historical Overview

The relevance for other societies of the Australian experience in responding to AIDS is difficult to assess. There are general approaches and specific policies and programs which offer useful lessons, but it is not always easy --even for Australians – to recognise the historical and cultural contexts in which these approaches, policies and programs have developed. The following account offers an interpretation of these contexts of the Australian response. No single account can claim to be definitive and there are alternative interpretations, with different emphasis and conclusions, put forward in the books and articles listed in the bibliography.

1. Preconditions of the Australian Response

Several features of the Australian health system and Australian culture had a significant influence on the way in which responses to AIDS developed.

Under the Australian constitution responsibility for health remains with the states, but the Commonwealth (national) government's power over taxes and its power to provide sickness and hospital benefits have given it strong central authority on health matters. Medicare, the program of universal health insurance introduced by the Commonwealth government in 1984, provides universal health insurance under which all permanent residents receive free medical services and short-term hospital care. However, the six state and two territorial governments remain responsible for providing health services, including hospitals, and there is substantial variation among them in the organisation, level and public-private division of responsibility for health services. Some measure of co-ordination is achieved through twice-yearly meetings of the Commonwealth and state ministers of health and their officials. Since 1996 detailed health agreements have been drawn up between the Commonwealth and each of the states which transfer a substantial measure of health priority-setting to the states .

Non-government organisations have a strong tradition of contributing expertise and influencing Australian government policy. In the first half of the century, this

was largely limited to economic and professional groups, but since the 1960s social groups concerned with environmental, women's and many other issues have been mobilised and have gradually achieved recognition for their expertise on matters of public policy. This recognition was closely related to wider acceptance of minority and marginal groups within Australia from the late 1960s and early 1970s, with the growth of concepts of Aboriginal citizenship, a multi-cultural society, equality for women and the decriminalisation of homosexuality. These concepts were built on longer term cultural values in Australian society favouring social equality and "fair play", as well as a pragmatic, non-ideological outlook which has inhibited the growth of ultra-conservative religious and political movements and limited their impact on public policy. In this respect, Australia proved to have much greater scope for innovative action on AIDS than, for example, the United States.

In health policy, the medical profession has had a strong voice through the government-funded National Health and Medical Research Council and through professional groups: the Australian Medical Association, a smaller Doctors Reform Society, and the Colleges of General Practitioners and of various specialist groups. From the 1970s despite the fact that government departments of health became staffed primarily by generalist administrators, replacing those with medical qualifications, the authority of the profession remained predominant and health consumers were not well organised or seen as significant participants in policy prior to AIDS.

During the 1970s a new concept of health promotion was developed throughout the world, focusing on the prevention of disease through community education in self-management for health maintenance. This involved a wider social and environmental view of health than the established approach of public health laws which focused on control through surveillance, testing, notification, contact-tracing, treatment (when available) and quarantine. The new view of public health gained support among some Australian health officials and doctors through the success of early harm prevention education programs concerning automobile seat belts and tobacco use. These programs were successful in part because of the broad acceptance by Australian society of government authority and government health messages, a cultural attitude not shared by the US and many other societies.

2. Putting AIDS on the public agenda

During 1981 and 1982, as AIDS was gradually identified in the US and France, some medical specialists and gay activists began to follow American news on AIDS. In view of the close links between Australian and US gay communities, it was assumed that AIDS would eventually appear in Australia. Announcement of the first Australian case in May 1983 coincided with a request from the Red Cross Blood Transfusion Service that homosexual men not contribute blood. This led to panic about AIDS in the media, and also to the mobilisation of AIDS Councils by gay communities, as well as appointment of a medical working party by the National Health and Medical Research Council to prepare guidelines for infection control, patient care and the collection of epidemiological data.

During the year of planning that followed, the US announced in April 1984 the isolation of the virus (later named HIV), which made possible the rapid development of a first generation of antibody tests. Because of their tradition of close relationships with US research centres, Australian scientists were among the first to obtain access to US tests, and testing provided awareness by July 1984 of a case of HIV transmission by blood transfusion; by October it was recognised that 30% of those using Factor VIII to treat haemophilia were HIV-positive. Because of its geographical isolation Australia had for many years been self-sufficient in blood and blood products, unlike most other countries. The Commonwealth government was closely involved in the funding of blood collection through the Red Cross Blood Transfusion Services, as well as the manufacture of Factor VIII through a government corporation. Government responsibility for the safety of the blood supply meant that AIDS quickly became a major concern for the Commonwealth government.

In November 1984, in the midst of a federal Parliamentary election campaign, the Queensland government announced that three infants had died after receiving HIV-contaminated blood collected from a gay donor. A conservative federal political leader immediately blamed the Labor government for the deaths. To prevent AIDS from becoming a political issue, and to block rising hysteria in media coverage of AIDS, the Commonwealth Minister of Health called an

extraordinary meeting with state health ministers to agree upon a set of initiatives. Blood donor-exclusion procedures, which had been developed in previous months, were standardised; the Commonwealth government funded the development of viral test kits, and arranged for Au stralian scientists to participate in the US evaluation of the kits; and both a medical AIDS Task Force and a National Advisory Committee on AIDS were established. The latter, given responsibility for devising education programs, included not only medical and legal experts, but also representatives of labour unions and health consumer groups: the Haemophilia Foundation and the Sydney and Melbourne AIDS Councils.

In this initial response to AIDS as a public issue, the staff of the Commonwealth Minister for Health played a crucial political role. On several issues, the Minister and his political staff had found the Department of Health unresponsive and too closely guided by the medical profession, which opposed the introduction of Medicare. The Minister's senior political adviser had followed AIDS issues as they developed, and established direct contact with relevant medical specialists and officials, as well as with the AIDS Councils. When AIDS suddenly became of critical importance, the minister's office was able to mobilise political resources and authority to respond with innovative measures.

During the next few years the Minister's office continued to guide the major initiatives on AIDS in a manner unusual in health policy-making, which was normally left to departmental officials. Recognising the value of involving health consumers in policy-making in order to balance the dominant position of the medical profession, the Minister provided funding and support not only to the AIDS Councils, but also to a new Consumers Health Forum and to joint medical-consumer groups: the Public Health Association and the Community Health Association. Later ministers saw these groups as useful allies in their negotiation with the medical profession.

3. Choice of Strategy

In the months after November 1984, there was extraordinary activity concerning AIDS. The Minister and senior officials visited the US for discussions in Washington and at the Centers for Disease Control and to view medical and community programs in San Francisco and New York; they returned determined not to allow the epidemic to have similar effects in Australia. Substantial resources were mobilised to have all Factor VIII heat-treated by January and the blood supply fully tested by the end of April 1985; no cases of HIV transmission by blood transfusion or blood products after that time has been identified.

In the Commonwealth Department of Health, which had recently been restructured to emphasise health promotion, an AIDS Co-ordinating Unit was established within the new Division of Health Advancement. The states responded in different ways. In New South Wales, AIDS remained one of many concerns in the office of the Director of Public Health, while in the ministries of health of Queensland, Tasmania and South Australia AIDS was allocated to offices concerned with sexually transmitted diseases and was dealt with through the traditional containment strategies applied to STDs. By contrast, AIDS was allocated in Western Australia and Victoria to health promotion branches, with quite different results in the early years.

In the health department of Victoria the director of health promotion considered that only gay men would understand the health education needs of gay men. Against opposition from medical specialists she hired two leaders of the Victorian AIDS Council to organise community education programs and she arranged to fund a Gay Men's Community Health Centre. This provided the Commonwealth AIDS Unit with a model for funding AIDS Councils for education and care programs. This action not only reflected recognition of the expertise that had developed within some Councils, but also the increasing force of the concept of health promotion through community education.

The rival approaches of medical containment and community education were embodied during 1985-87 in the two advisory committees. The chairman of the medical AIDS Task Force claimed authority concerning AIDS issues and he argued forcefully for testing "risk groups", the only available medical response. On the

other hand the National Advisory Council (NACAIDS), with its strong community representation, preferred community-based education in the absence of any available treatment for those whom testing showed to be HIV-positive. The Minister's office and the Commonwealth Department of Health supported the NACAIDS position, and the Minister's office succeeded in insulating the issue from partisan politics by establishing and educating a Parliamentary Liaison Group on AIDS with members from all political parties. Nonetheless, the Commonwealth government's commitment to a health promotion strategy on AIDS had to be reasserted frequently in the face of continued insistence on mandatory testing and medical control of AIDS policy by some sections of the medical profession.

The state ministers agreed in May 1985 to a brief statement of strategy emphasising education and they agreed to match Commonwealth funding for state AIDS programs. All but conservative Queensland agreed to help fund the state AIDS Councils. During a final bout of media panic over the first case of HIV in schools and other incidents in mid-1985, the Premier of New South Wales insisted on legislating for compulsory notification of antibody test results and criminal penalties for knowing transmission of the virus. These measures proved unworkable when doctors refused to violate patient confidentiality.

Community education programs developed rapidly. The Victorian AIDS Council, which had developed considerable expertise in 1983-84, drawing on US community experience, worked closely with the Victorian government's Health Commission. Early in 1985 it organised a model campaign on safe sex for gay men, emphasising the use of condoms. In Sydney, despite several initiatives within a much larger gay community and a much larger AIDS caseload, both community and government responses were diffused among a number of organisations. Only after 1987 did the AIDS Council of New South Wales, working with a new state government AIDS Bureau begin to set the pace in AIDS program innovation. From 1986, the community-based AIDS Councils established a national Australian Federation of AIDS Organisations (AFAO), supported by Commonwealth government funds, which gradually achieved a reputation for developing pragmatic policies.

The perceived success of community education among gay men led governments to support programs for other groups seen as being at risk. In New South Wales,

as early as 1986, drug services made needle exchanges available for drug users, and the Australian Prostitutes Collective in Sydney was funded for condom education and distribution. Neither of these arrangements raised public controversy and they were gradually adopted in other states. These early interventions were later credited for the continuing low rates of HIV infection among drug users and sex workers and their partners in Australia compared with those in other industrialised societies. They helped lead to the formulation of a strategy of harm reduction in relation to drugs, coherent with the principles of health promotion.

Most early AIDS education programs were developed by and for gay men. However, at the Paris international AIDS conference of July 1986, it was finally agreed by medical experts that HIV was transmissible by vaginal intercourse. Western governments responded by beginning to fund public education on AIDS. In Australia a NACAIDS sub-committee was given responsibility for negotiating with media and advertising agencies a major campaign focused on a television advertisement, The Grim Reaper. This was broadcast in April 1987 and proved controversial because of its shocking images, the failure to carry through with a planned follow-up campaign, and because of a rise in discrimination against gay men and people living with AIDS. Nonetheless the Grim Reaper served to place AIDS and condom use on the wider public agenda and it helped to mobilise school and church education programs. It also persuaded Commonwealth politicians and officials to commit much more substantial funding to AIDS programs.

The national and community AIDS education programs, of which the Grim Reaper was only one among many, helped to create a greater public willingness to address sexual health , sexuality, sex work and even drug use in an open and pragmatic manner. Issues which had not been considered appropriate for public discussion, such as condom use, rapidly became matters for rational debate in the public media, in schools and in churches.

4. Consolidation of Policies in a National Strategy

Australian policies on AIDS were beginning to receive recognition among other countries for their innovative character. In July 1987 the first regional conference on AIDS for Asian and Pacific island states was organised in Sydney by the Commonwealth government and WHO's new Global Programme on AIDS, raising the Australian response to AIDS as an appropriate model. This was the first occasion for ministers and officials to view Australian programs, and it was followed by many study tours from the region, especially after the first Asia-Pacific AIDS conference, held in Canberra in 1990.

For two years after the Commonwealth election of July 1987, national policy-making on AIDS was focused on the process of developing a long-term strategy that would provide for long-term commitment of funding and lock the recalcitrant states of Queensland and Tasmania into established national priorities. Again, much of the initiative and co-ordination for this exercise stemmed from the office of the Commonwealth Minister for Health. A new institutional framework was developed during the latter half of 1987. When the chairs of the Task Force and NACAIDS retired, these bodies were replaced by a new Australian National Council of AIDS (ANCA), advising the Minister, and an Intergovernmental Committee on AIDS was established among state and federal officials to negotiate agreement on unsettled or difficult issues, such as prison programs and law reform, that lay within the jurisdiction of the states.

During 1988, while a discussion paper was being written as background to a national strategy, the Third National Conference on HIV/AIDS was held in Hobart. Previous national conferences in 1985 and 1986 had served to consolidate a national community of interest in AIDS, but the 1988 conference was deliberately designed to canvas a range of outstanding issues. It provided the occasion for an unusual attack on the direction of AIDS policies by the Parliamentary opposition spokesperson on health, arguing for greater medical control, but he was shortly thereafter replaced and bipartisan policy was resumed. The conference also provided the occasion for encouraging the mobilisation of communities at risk which had remained unorganised: commercial sex workers, injecting drug users and people living with HIV and AIDS. Officials in the Minister's office took the initiative in convening and funding national federations of community

organisations for each of these and arranging their affiliation with the Australian Federation of AIDS Organisations.

The first step towards a National Strategy on HIV/AIDS was the preparation of a discussion paper, "AIDS: A Time to Care - A Time to Act". Drafted by a team of consultants experienced in AIDS programs, this document laid out in 256 pages the options available concerning each policy area and it proposed a set of guiding principles. After the paper was discussed by parliamentary committees and community groups in all states, six panels on key issues -- indigenous people, drug use, antibody testing, discrimination and other legal issues, education and prevention, and treatment and care -- held public hearings throughout the country and prepared reports. This exercise served a broad educational purpose and opened up the range of issues considered by drawing in the lessons of practical experience from all communities.

The National Strategy was then drafted by a group within the Commonwealth Department, working to a steering committee of officials and others. As with the discussion paper, draft sections of the Strategy were discussed at an early stage with a National AIDS Forum of 33 people drawn from all areas of interest in AIDS, ensuring wide consultation on all issues. Despite pressure from some doctors for mandatory HIV testing of surgical patients and aggressive contact tracing, the National Strategy rejected medical control over AIDS. Presented to Parliament in August 1989, it was welcomed by the Parliamentary opposition. It confirmed the existing thrust of AIDS policy, requiring informed consent and confidentiality for testing and advocating extension of needle exchange and condom distribution. It also adopted the discussion paper's guiding principles, which have been repeated in many other countries. The Commonwealth committed itself to four years of funding, rising from $31 million to almost $68 million per year.

The long process of consultation leading up to the National Strategy consolidated established policies and identified areas requiring further work. It confirmed a close working relationship between the Commonwealth government, AFAO and a number of key state officials and clinical doctors working with AIDS. It did not, however, completely end the demand within the Australian Medical Association for medical "ownership" of AIDS policy. That claim continued to resurface without success.

Shortly after adoption of the National Strategy the Commonwealth Minister left the health portfolio after seven years, and several key officials transferred to the states or to other fields. This marked the end of the exceptional political intervention in AIDS policy. Succeeding Ministers of Health had other priorities, and AIDS policy-making within the directions set by the National Strategy was left to public servants.

5. Maintaining Partnership and Commitment

During the 1990s collaboration among government officials, health professionals and AIDS-affected communities became known as the HIV/AIDS Partnership. The various consultative arrangements during the two years of preparation for the National Strategy involved all three groups on a basis of equality of expertise and a wide measure of mutual respect. But it was not always easy to maintain a sense of common enterprise in the face of changing government priorities and competition for funds.

Although the National Strategy of 1989 confirmed the directions which had been taken in previous years, several new initiatives stemmed from the Strategy. The Intergovernmental Committee on AIDS began collaborative planning among the states on the difficult issues of prison and school programs and education among youth and indigenous communities. The most successful of these was a review of all areas of law reform required for conformity with the principles and detail of the National Strategy. Although implementation of the proposed reforms has been only partial, this comprehensive review provided a set of documents which other countries have found useful.

One issue which was not mentioned in the National Strategy, but which arose shortly afterwards, was access to new AIDS treatments. Australia has maintained a strict regime of pharmaceutical import controls, particularly after the thalidomide episode. Although the Commonwealth was quick to make AZT available, other new treatments available in the US required lengthy approval procedures. ACT-UP, a small radical group of people living with HIV/AIDS, modelled on ACT-UP in the US, staged protests over several months in 1990 and these, with support from the AIDS Councils, persuaded the Commonwealth government to modify the approval procedures of the Therapeutic Goods Administration.

Community education programs multiplied among all groups within the Australian population, becoming more detailed and specific to suit variations among community cultures. Most of these were peer education projects developed by community groups bidding for Commonwealth and state government grants, and later contracts. The Australian Federation of AIDS Organisations (AFAO) and its member Councils developed a large pool of

expertise, which was made available to other groups, and its monthly National AIDS Bulletin circulated information on policy developments and program innovations. Although these community education programs were well funded, a greater amount of funding was for many years spent on national education programs commissioned by the Commonwealth Department and broadcast through public media, despite widespread agreement that community education programs were much more effective. On some occasions programs with explicit messages about safe sex among gay men aroused conservative opposition. This sometimes embarrassed state governments, but these occasions did not stop the gradual development of wider public tolerance of open discussion of sexual matters.

The growth of AIDS funding produced very large organisations in the AIDS bureaux of Departments of Health and in AFAO and some AIDS Councils. In the 1990s all of these became increasingly bureaucratic and professional, provoking conflict in some Councils between employed staff and volunteers. Partnership meant close collaboration between government officials, health professionals and the Councils, and the latter became more like extensions of government and less like the community-based associations of the early years. Since the policy and program effectiveness of the Councils depended on their understanding of their own communities and their capacity to speak for those communities, much effort went into ensuring that they remained in close contact with changes in the communities.

Social research played a major role in understanding changes in attitudes and behaviour, particularly among gay men, who constituted 86% of those with HIV. From 1987 the first round of government-funded AIDS research projects included one jointly designed, implemented and interpreted by the AIDS Council of NSW and researchers at Macquarie University. This project, combining qualitative and quantitative approaches, revealed the range of current practices and understandings among gay men in Sydney. The results of this and later research projects were fed directly into government policy and community education programs. This served as a model for a widening range of community-based research projects not only in Australia, but throughout the world.

The major strains on Partnership during the 1990s arose from changes in government priorities. Framing the Second and Third National Strategies

provided the clearest evidence of shifts in the balance of the Partnership. The First Strategy ran from fiscal year 1989/90 to 1992/93. Early in 1993 the Commonwealth Department and the Australian National Council on AIDS produced separate rival drafts for a Second Strategy, and the Department circulated only its own draft to the states for comment. Relations between the Department and AFAO were almost broken off, but negotiation produced a compromise document and the next years saw the restoration of a very close working partnership as the Department's HIV/AIDS and Communicable Diseases Branch reached its most effective period.

There were always pressures from other health areas to reduce the priority in funding and staff resources given to AIDS, but the First and Second Strategies gave assurance that these resources would remain dedicated to AIDS. There were several periods in which "mainstreaming" of AIDS programs by absorbing them into broader programs was discussed, but not until 1996 was this seriously undertaken. Up until then the relative success of AIDS policies and their community orientation meant that they were held up as a model for other health sectors. In 1996 a major restructuring of the Commonwealth Department coincided with the first change of government since 1983 and with the drafting of a Third National Strategy. The managerial reorientation of government and the transfer of many operational programs to the states meant that the work of the AIDS Branch was diffused within a National Centre for Disease Control which focused on a much wider range of public health issues.

The Third National HIV/AIDS Strategy was preceded in 1995 by the first major evaluation of Australia's AIDS response. Conducted by Professor Richard Feachem, (who was about to become the World Bank's first Adviser on Health), the evaluation provided strong support for the previous National Strategies and recommended continuing priority for education and prevention programs for homosexually active men, as well as greater attention to programs for indigenous people. The Third Strategy, like the Second, was drafted within the Department with limited consultation, again creating tension in the relationship between the Commonwealth and AFAO..

The main innovation of the Third Strategy was its extension beyond AIDS to cover related diseases, specifically other sexually transmitted diseases and hepatitis C, which had spread rapidly through drug use and blood. The Australian National Council on AIDS and the Intergovernmental Committee on AIDS both had Related

Diseases added to their titles and responsibilities, and funding was provided to the National Aboriginal Community Controlled Health Organisations and a new national non-government organisations, the Australian Hepatitis Association. Some of the smaller state AIDS Councils broadened their responsibilities to cover sexual health and hepatitis, while in the larger states with higher HIV/AIDS caseloads they remained focused on gay men.

More important than the Third Strategy in absorbing HIV/AIDS into mainstream public health programs has been the transfer of responsibility from the Commonwealth to the states for all public health programs. From 1 July 1997 Public Health Partnerships between the Commonwealth and the states came into effect. Under these the Commonwealth provides each of the states and territories with annual funds for public health without specifying the amounts to be spent on specific program areas such as HIV/AIDS. The states are given wide discretion in deciding which programs to fund, within broad performance indicators negotiated between the Commonwealth and each state. This arrangement will test the extent of commitment in each state to the objectives of the Third Strategy, particularly to those concerning harm reduction.

6. Conclusion

The HIV/AIDS Partnership remains intact, and retains much of its original force in states with large caseloads such as New South Wales and Victoria. However, the new managerial approach in government places less emphasis on consultation in policy-making and is less concerned with consumer representation. The concept of peer-based education has become strongly entrenched in public health practice, and the professionalism of AFAO and its constituent organisations has ensured that they continue to play a significant role in the design and delivery of programs in Australia and internationally. It remains to be seen whether the new decentralised public health system is capable of responding to a new threat comparable to HIV/AIDS in the way in which Australia responded in the late 1980s.