



**AUSTRALIAN HEALTH POLICY
INSTITUTE**
at The University of Sydney

AIDS in Australia: The Primitive Years

**Reflections on Australia's policy response to
the AIDS epidemic**

The Hon. Dr. Neal Blewett, AC

AUSTRALIAN HEALTH POLICY INSTITUTE
Commissioned Paper Series
2003/07

ABOUT THE AUTHOR

The Honourable Dr. Neal Blewett, AC

After a distinguished academic career, including a period as Professor of Political Theory and Institutions at Flinders University, Neal Blewett entered Federal Parliament in 1977 as Labor member for Bonython. In 1983 he was appointed Minister for Health in the Hawke government and over the next seven years was the political architect of Medicare, and was responsible for the development of Australia's AIDS policies and for a greater emphasis in national health policies on the prevention of diseases. Later he served as Minister for Trade and Overseas Development and as Minister for Social Security.

Retiring from Parliament in 1994, Neal became Australian High Commissioner to London in that year, as well as serving on the Executive Board of the World Health Organisation between 1995 and 1998. He is a visiting Professor in the Faculty of Medicine at Sydney University, President of the Alcohol and Other Drugs Council of Australia, President of the Australian Institute for International Affairs and Chairman of the Eleanor Dark Foundation. In between these activities, he gardens in the Blue Mountains.

CONTENTS

AIDS in Australia: The Primitive Years4

Reviews by:

Professor Ron Penny21
Mr Lou McCallum28
Dr John Ballard35

AIDS IN AUSTRALIA: THE PRIMITIVE YEARS

This is a hybrid work—part personal memoir, part public policy essay and part political science analysis. It aims to provide a framework for the study of policy making in relation to AIDS during the early years of the epidemic in Australia—what I have called ‘the primitive years’. Health policy is rarely, if ever, made with perfect knowledge—for one thing one can never predict with total confidence the consequences of societal interventions. But rarely has policy been made with so thin and contested an information base and with societal mechanisms so inadequately prepared and reluctant to take on the task as in the early years of AIDS policy making.

The coming of AIDS to Australia was roughly coincident with the arrival of the Hawke Labor Government in Canberra. Only Ian Sinclair, then leader of the National Party, saw a causal rather than a coincidental relationship in this juxtaposition, blaming AIDS ‘on the promotion of homosexuality as a norm by Labor’.¹ The result of this coincidence was that the new government was handed a disease problem about which little was known—and much of that contested—and, through no fault of our predecessors, a blank slate as regards policy.

While I had been vaguely aware, through reading magazine articles, of an odd disease affecting male homosexuals in the United States, my first formal encounter with AIDS came on 12 March 1983, the day after the swearing-in of the first Hawke ministry. In an all-day meeting in a committee room of the old Parliament House I met with the secretary of the Health department and some twenty of his senior officers—the numbers fluctuating and the officers changing during the course of the day. Presenting me with two fat folders with issues numbered from one to about forty they proceeded to brief me on the major health issues facing the new government, the officers competing to display a detailed knowledge of the Labor Party health platform that rivalled that of the minister.

The government had a full health agenda—the introduction of Medicare, changes to the Pharmaceutical Benefits Scheme (PBS), a revival of the community health program—so it was not until mid-afternoon that somewhere in the second folder we came upon something called GRID—Gay-Related Immune Deficiency. It was explained to me that a mystery disease that manifested itself in an unusual form of cancer or a distinctive pneumonia had affected clusters of male homosexuals

¹The Canberra Times, 17 November 1984. The Premier of Queensland, Joh Bjelke-Petersen, agreed. ‘The Labor Party is...to blame with their acceptance of that type of low and disgusting life style.’ *The Canberra Times*, 4 December 1984

in the United States, both related to deficiencies in the immune system. The aetiology of the disease was unknown. Was it environmental, a product of the homosexual lifestyle? Was it bacterial or viral in origin? There were no answers. I was informed there had been no cases in Australia and that it was not anticipated that it would be a significant health problem in Australia. In fact there had already been one case in Australia and AIDS was to become the most significant disease problem, as distinct from health-financing problem, of my time as minister.

1983–84 were turbulent years in Australian health politics with the introduction of Medicare and the battles surrounding it. As far as the general public was concerned, AIDS was merely a background rumbling, with few realising that it portended a coming storm. By the end of 1984, 47 cases had been diagnosed and 18 people had died of the disease. The combination of blood, sex (and deviant sex at that), and death of course, proved irresistible to the media. There was a sprinkling of sensational stories and lurid headlines—frequently sourced from the United States where, of course, the epidemic was far more advanced.² Indeed my first public intervention on the issue was to chide *The Medical Journal of Australia* for succumbing to the media hysteria with its cover story on ‘The Black Plague of the Eighties’, accompanied by symbols of death and a montage of the more sensational press headlines.³

But behind the scenes, particularly after the confirmation of the viral nature of the disease, concern was rising over the blood supply. From mid-1983 action was beginning to be taken to discourage high-risk donors from giving blood. On 12 May I wrote to all State health ministers advising that it would be prudent to ask male homosexuals, particularly those with multiple partners, to voluntarily refrain from donating blood. A fortnight later the National Blood Transfusion Committee, chaired by Professor David Penington, recommended that blood transfusion centres not collect blood from ‘sexually active homosexual and bisexual men with multiple partners, present or past abusers of intravenous drugs and sexual partners of any of these groups’.⁴ Although this step was taken at the national level earlier than in any other country it was still tragically late.⁵

² There is a useful article by Evan Whitton surveying early newspaper coverage in *The Sydney Morning Herald*, 17 August 1985

³ See *The Medical Journal of Australia*, 11 June 1983, Ministerial press release, 28 June 1983. The editor protested, with some justice, that the intention was ‘ironical’ but after a steady stream of protests to the journal over the next few issues confessed that in politics ‘a little irony is a dangerous thing’. *The Medical Journal of Australia*, 15 October 1983

⁴ *The Age*, 3 June 1983

⁵ The proportion of haemophiliacs receiving blood products and who were infected with the virus was about 30 per cent—one of the higher rates in the developed world. See *The Medical Journal of Australia*, 8 July 1985 for an early recognition of the dimensions of the problem

Moreover, its implementation was inhibited by a number of factors. In practice it was not easy for the blood centres to ensure compliance with the edict and the ‘multiple partners’ qualification was to prove dangerously misleading, while gay groups protested at the discrimination involved. The Red Cross was highly dependent on young male donors and was fearful of driving them away by intrusive questionnaires, as well as of alarming donors more generally. As one official put it, ‘we have to watch our public relations with donors’.⁶ Again in the United States, the country with the biggest case load, it remained the official view that ‘there is no clear-cut evidence to show that AIDS can be transmitted through blood transfusions’⁷ and this view undoubtedly influenced Australian attitudes. There was, too, a misplaced confidence in the Australian blood supply. ‘The risk of transmission of this disease by blood and blood products in Australia’, observed Professor Penington, ‘is greatly reduced by the exclusive use of volunteer blood donors.’⁸ On a related front the introduction of Factor VIII had so transformed the lives of haemophiliacs that specialists were reluctant to confront the threat that the product might be tainted.

Then, in November 1984, on the eve of a federal election, came the death of four babies in Queensland as the result of an HIV-infected transfusion. This event catapulted AIDS into the headlines and to the forefront of the political agenda, where it remained for the next half-dozen years. That the response took the form of a national policy was, given the Australian constitution, unexpected and contrasts dramatically with two other federations—the United States and Canada—where at least until well into the epidemic the national governments remained largely on the sidelines, spectators rather than directors of policy.⁹ The reverse occurred in Australia in part, at least, because other potential stakeholders were reluctant to press a claim, or at least any exclusive claim.

The usual owners of disease in our society are the members of the medical profession. It is the prestigious groups of well-organised clinicians—cancer specialists, kidney or cardiovascular experts—who greatly influence public policy in the treatment of their disease. To begin with there was no established

⁶ *The Sydney Morning Herald*, 26 July 1984

⁷ *The Age* 19 May 1983. The denial by American authorities of the blood transfusion route is fully documented in Randy Shiels, *And the Band Played On*, St Martin’s Press, 1987; Penguin 1988, parts V and VI.

⁸ *The Age*, 3 June 1983

⁹ President Reagan’s refusal to address AIDS, even indeed to mention the word, became notorious and was indicative of the national government’s response to AIDS; while in Canada in 1988 the federal health minister was burnt in effigy, a reaction to the federal government’s failure to articulate a national AIDS strategy. For a useful study of US and Canadian policies set in a comparative context see David L. Kirp and Ronald Bayer, *AIDS in the Industrialized Democracies*, pp 7–98. The Australian chapter in this book is written by the leading Australian authority on AIDS history, John Ballard, and is a good summation of his views

network of AIDS specialists; only over time was this built up with the diversion in mid-career of able specialists to AIDS work, the involvement of others whose specialities impinged on the disease—for example immunologists, haematologists—and the entry of young physicians to make their careers in AIDS medicine.¹⁰ The disease itself tended to affect marginalised groups in the society and was handled by doctors who it is perhaps not fanciful to see as marginal to the medical establishment—inner city GPs, venereologists and specialists in haemophilia.

In addition the official organisation of the profession, the Australian Medical Association (AMA), was in full trade union mode, engaged in a battle with the government over Medicare. Issues of health as such were low on the agenda of the federal AMA in the course of the 1980s. I can recall no significant intervention by the national AMA into the AIDS debate until 1989. Then the slogan ‘surgeons in danger’, while it may well have reflected genuine concerns among surgeons, was as well a rallying cry in a campaign to unseat the existing powers within the federal AMA and possibly the national government, or at least its obstreperous minister. Moreover, the AMA tended to reflect the formal division of health powers within the constitution so that many of the state branches were active in the AIDS conflicts at state level. There was no uniform policy response among the state branches of the AMA, state branches both supporting and attacking the policies pursued under the aegis of the federal government.

The bulk of the medical profession was little touched by AIDS and a significant minority not particularly well informed; indeed governments probably underestimated the need for education within the medical profession. As late as 1989 a survey of GPs found that 25 per cent did not want to treat AIDS patients; 20 per cent feared infection from giving treatment; and 33 per cent could not provide adequate answers on how to inhibit the spread of the disease.¹¹

Under the constitutional division of powers the states are responsible for the management of diseases, though the constitutional allocation of the quarantine power to the Commonwealth has given the federal Department of Health a foothold in the management of infectious diseases. But the bureaucratic owners of disease in our society are primarily the state administrations. While the states are usually pugnacious defenders of their constitutional allocations, they were uncharacteristically unpossessive about AIDS.

¹⁰ The creation of an AIDS profession in Australia would make a fascinating prosopographical study

¹¹ See *The Medical Journal of Australia*, June 1990

The state health portfolio is a graveyard, many a promising career having ended prematurely in this portfolio. In modern times only one person who has occupied the health ministry has ever gone on to be premier.¹² Because of the secular and religious passions that seethed around AIDS, the disease added an ideological dimension to a portfolio that was already an administrative nightmare. In such an ideological maelstrom ministers could easily drown.

The marginal nature of the groups affected may also have influenced state attitudes. It was, I suspect, only partly a joke when a state ministerial colleague commented to me, 'Look, mate, there are no votes in buggers, druggies and prozzies!' To further complicate matters, for some state health ministers in three of the states the chief mode for the spread of the disease—male-to-male sex—was an illegal activity. This did not matter much in Tasmania where there were few cases, nor in Western Australia where the prohibition was handled with pragmatic panache. But in Queensland the law and the attitudes behind it dominated the political approach to the epidemic. In addition, in all jurisdictions a second mode of transmission—the use of needles in illegal drug injections—was also proscribed.

But it was concern about costs that probably most explains the states' uncharacteristic readiness to cede health turf to the Commonwealth. In the course of 1983–84 the original complacency about the disease within the health bureaucracies and among the medical advisers to government had been transformed and, if anything, the likely impact of the disease was exaggerated. The financial impact of such case loads on the already strained health budgets of the States made them desperate for, at least, the fiscal involvement of the federal government.

Finally, in 1984, four of the six state governments were in Labor hands, and the State ministers had campaigned with their new Commonwealth colleague on a number of issues, particularly Medicare. Moreover as they were nearly all new ministers the inevitable stresses of government had as yet not eroded personal relations so that there was a remarkable degree of fraternal amity. I was well aware of the expectations of my state colleagues that the Commonwealth would share with them the burden of combating this unknown and frightening disease. And in case I was not, Neville Wran was merely the most vocal Premier pressing the Prime Minister for Commonwealth involvement.

¹² The exception was Michael Ahern, who after a brief period as Health minister became for a short period Premier of Queensland

The Commonwealth emerges as the chief owner of the disease between the summer of 1984 and the winter of 1985; the critical dates are the national AIDS summits of late 1984, occasioned by the Queensland baby transfusion cases, and the Commonwealth budget of August 1985, with for the first time a significant commitment of moneys to AIDS. The fact that the Queensland crisis had occurred on the eve of the 1984 federal election probably hastened the emergence of the Commonwealth in a leadership role.

In between these dates I made a Christmas–New Year visit to the United States, which was the single most significant influence on my own views about AIDS.¹³ I can identify three aspects of the American situation that affected my thinking. Firstly, I preferred the Californian cooperative approach to the more traditional public health model adopted in New York. The former was characterised by a partnership between the medical profession and the affected communities, with as great an emphasis placed on education as on medical control, with the integration of the gay community into both public health campaigns and aspects of service delivery. By contrast the New York model placed greater emphasis on medical control and dominance, and ascribed a lesser role to the affected communities. Secondly, I was alarmed by the bitter politically partisan debates that raged over AIDS in the United States and hoped we could avoid those in Australia. Thirdly, the anger against Reagan over his failure to address AIDS confirmed me in the wisdom of our decision to adopt a national approach.

From 1985 onwards it is possible to distinguish four distinct patterns of Commonwealth–State relations in the handling of the disease.¹⁴ In Victoria, South Australia and Western Australia with strong state health ministers and supportive premiers, a close and cooperative relationship in policy and programs developed between the Commonwealth and the states. All pursued a liberal, cooperative and inclusive approach, working closely with the affected communities, placing major emphasis on education and eschewing most forms of legislative intervention. There was little friction over national policy and programs while all three states took creative and imaginative initiatives within the overall national framework.

In New South Wales with a powerful premier, subject to bouts of populist passion, and a submissive health minister, relations were more ambiguous.

¹³ This visit was originally planned as part of an international trip to explore options for drug policies on which the government was working. With the Queensland crisis, the USA section of the itinerary was transformed to focus almost entirely on AIDS issues

¹⁴ There is a good review of State programs in Milton Lewis, *Thorns on the Rose*, pp 448–57 though Dr Lewis would not necessarily agree with the classification offered here

There were rhetorical flourishes to outbid Queensland with draconian sanctions. In November 1984 Wran raised the possibility of legislation ‘twice as tough’ as Queensland’s,¹⁵ while the 1986 legislation requiring doctors to identify to the state health authorities all individuals testing positive probably weakened both the testing system and the comprehensiveness of the reporting data. But aside from these sporadic initiatives from on high and a comparative tardiness in introducing education programs, the NSW approach remained very much within the mainstream.

In Tasmania a third pattern emerges. There was some troglodytic rhetoric and much literature produced under the auspices of the Commonwealth was too daring for the Tasmanian psyche. But practices behind the rhetoric were low key and pragmatic. The Liberal government there did not seek to emulate the Queensland government with hasty and knee-jerk legislation and followed a modified version of the mainstream agenda. Anyhow, as noted above, the case load in Tasmania was low.

Between the Commonwealth and Queensland there existed a state of cold war. Queensland practised everything the Commonwealth discouraged: the authoritarian traditional public health approach with identification of the infected and contact tracing backed by legal sanctions; stigmatisation of the afflicted,¹⁶ and knee-jerk, ill-prepared legislative responses which were probably counter-productive in handling the disease.

Queensland balked at everything that the Commonwealth encouraged. There was no cooperation with the gay organisations as they were composed of illegals. There was little state education of at-risk groups on the grounds that it would encourage deviant behaviour.¹⁷ Indeed there was minimal emphasis on education, particularly for young people, and what existed was often farcical. When AIDS education was at last permitted in Queensland schools—in April 1987—the Education Minister instructed teachers that the program would not include any sex education. ‘If a student asked what sexual intercourse was the teacher should refer the student to a medical practitioner or health expert.’¹⁸ All best efforts were made to keep condoms out of the hands of the masses so that when Queensland university students—in defiance of a ban—installed condom vending machines the state police ripped them out.¹⁹

¹⁵ *The Australian*, 17 November 1984

¹⁶ See the comments of Bjelke-Petersen reproduced for southern edification in *The Age*, 24 November 1984

¹⁷ Lewis, *Thorns*, p.446

¹⁸ *The Courier-Mail*, 28 April 1987. *The Courier-Mail*'s comment on this was that it ‘was like trying to teach [students] to write without a pencil’, 29 April 1987

¹⁹ *The Australian*, 2 September 1987

That this incipient cold war did not become a hot war was due to two factors. First there was the inherent civility of the Commonwealth Health Minister. I even denied the tempting request proffered by the Queensland trade unions that I set up condom vending machines in all Commonwealth-owned buildings in Queensland. The second factor was the capacity of an able and courageous group of senior Queensland health officials to ameliorate these policies as they were practised on the ground.

It is important to note that the Commonwealth health bureaucracy was not particularly enthusiastic about or well equipped to take over the ownership of AIDS. There were natural fears about opportunities for significant cost shifting by the states. These were almost immediately realised when within weeks of the November 1984 summit the Queensland Health Minister sought to blackmail the Commonwealth into paying for the computerisation of the Queensland blood banks,²⁰ a task already carried out by most of the other states at their own expense. Among some of the older senior officials there was a preference for the Commonwealth playing a back-up role rather than a lead role.

Nor was it a particularly distinguished bureaucracy: as my original briefing on AIDS suggested it was lacking in imagination and foresight. This was not unexpected as it was very much a second level department, a status influenced by the fact that Department of Health was not a Cabinet department, this being the chief determinant of the status hierarchy within the Canberra bureaucracy. Only once since 1956, and then only briefly, had the health minister ever been a member of the Cabinet.²¹ This meant in turn that the department was less likely to attract the able young graduates making a career in the federal civil service. Moreover, the requirement, only abolished in 1982, that the head of the department be a medical doctor, foreclosed the position to the ablest figures in the public service.

The Commonwealth department too, like the state health bureaucracies, had been affected by the atrophying of public health in Australia. The federal Department of Health had had no significant experience of infectious disease since the poliomyelitis epidemics of the 1940s and 1950s. Infectious disease expertise was therefore thin on the ground. The only health institutions regularly pursuing traditional public health clinical practices were the various state VD clinics.

²⁰ See comments of Queensland Health minister, Brian Austin, *The Courier-Mail*, 19 November 1984

²¹ Senator Harrie Wade in 1963–64

If there was a general reluctance on the part of obvious elements to claim ownership of AIDS and in the case of the Commonwealth, a suspect competence, AIDS was not left an orphan. First there were the physicians at the coalface, those actually dealing with the growing number of AIDS cases, who became leading advocates demanding that governmental attention and resources be directed towards AIDS. These physicians were mostly drawn from specialities relevant to the disease, often making courageous decisions in mid-career to focus on this new disease. Ron Penny, Roger Dawkins, John Dwyer were immunologists, Ian Gust a virologist, Basil Donovan and David Bradshaw venereologists, Julian Gold an epidemiologist while the younger David Cooper was an AIDS specialist from the beginning of his career.²²

Australia was well served by its leading AIDS specialists. Not only were they responsible for the on-the-ground implementation of the AIDS policies but also they were key figures in the conception of those policies, and leading public advocates for and defenders of them. Even if their volubility before microphones and cameras in this last role added at times to the problems of a harassed minister this was a small price to pay. A myth grew up in the media at the time and frequently occurs in later analyses that Australia's liberal, non-judgmental, inclusive community-based approach to AIDS was imposed by the minister and a dubious coterie around him on a defiant medical profession, who wished for some more explicitly medical model. This caricature was given credibility by the frequent attacks on the policy by medical men: by proponents of old-style public health approaches, by conservative doctors and by doctors with political axes to grind. It was given wings when a leading medical adviser to the minister lent his authority to the cause.

The only alternative model, as distinct from differences of emphases within the prevailing framework, was the authoritarian contain-and-control strategy deriving from traditional public health with its emphasis on identification of the infected, contact tracing and if necessary quarantine. This was certainly a model with the medical men on top, with much less dependence on cooperation and policy input from the affected groups, and with a lesser emphasis on education. This approach was pursued in relation to AIDS with varying degrees of sophistication only in Sweden, Bavaria and locally in Queensland. This model was never pushed by the leading AIDS specialists in Australia, indeed it was implicitly rejected by them.

²² This list is not intended to be in any way comprehensive nor some kind of honour roll but merely to illustrate the variety of medical backgrounds from which the early specialists were drawn.

The clearest evidence for this is the almost universal resistance by the AIDS specialists to Neville Wran's proposal to put in place the necessary first plank of a contain-and-control policy—the identification and reporting of those carrying the virus—in mid-1985. Indeed the medical opposition to these proposals was so wide-ranging and vociferous that Wran, while not abandoning the legislation, was compelled to make major amendments. This suggests that it was always a furphy that the medical profession, or at least the AIDS professionals, had a politicised policy imposed on them and that somewhere round the corner there was an alternative medical policy to be pursued if only the minister could be circumvented. Rather, the policies followed in Australia were as much the policies of the AIDS specialists as they were those of the minister.

A second group to fill what I have called the 'ownership gap' were the committees set up to advise governments, committees which played an unusually influential role in the early stages of the epidemic because of the inadequacies of the bureaucracy confronted with an unknown infectious disease. At the national level the most important of these were the National AIDS Taskforce and NACAIDS—the National Advisory Committee on AIDS.

The Taskforce was essentially a continuation of the working party on AIDS set up by the NH&MRC in June 1983 but now—at the summits of late 1984—elevated in influence and status by being made a committee responsible to the Australian health ministers. This last point was important: by being responsible to all eight ministers the Taskforce in practice was responsible to none, and in its day-to-day activities was relatively untrammelled by ministerial interference. The suggestion that the Taskforce should contain gay representation, advanced by some of the gay groups, was rejected as I and my fellow ministers conceived of the Taskforce—perhaps naively given the inevitable social construction of the disease—as a purely scientific body giving unbiased scientific advice to governments. As well, Queensland had made it clear that it would veto any proposal for gay representation.

The Taskforce contained many of the physicians already mentioned but was chaired by a more senior figure, David Penington, Dean of Medicine at Melbourne University. Penington, a haematologist, was not an AIDS specialist and treated no AIDS patients and this was sometimes held against him. But to me this seemed an advantage for it placed him outside the often-intense rivalries and conflicts of interest among the AIDS specialists themselves. Moreover, Penington had been with the issue from the beginning, first as chairman of the Red Cross National Blood Transfusion Committee and then as chairman of the NH&MRC working party.

Beneath an unassuming exterior, Penington was a man of considerable ambition, steely determination and great intellectual self-confidence. He had a great appetite for work and for publicity. He had an outstanding capacity—both in prose and verbally—for the lucid explanation of complex issues, yet this was done without condescension. In the first four years of the epidemic he was the most quoted public figure on the disease. Grave, measured and authoritative his media statements and his influence did much to moderate the alarmist and hysterical outbursts that frequently engulfed the media in the early years.

Unlike the Taskforce, the second major national committee, NACAIDS, was directly responsible to the federal minister. This committee was designed to advise the minister on educational and social responses to AIDS and I wanted to use it to signal to the affected communities the government's commitment to a cooperative approach at the highest level by including their representatives. It thus included gay and haemophiliac representation as well as figures aware of drug issues. Because of the gay representation it would have been unacceptable to Queensland as a committee of the Australian Health Services Council. It was thus more responsive than the Taskforce to ministerial direction.

NACAIDS had in Ita Buttrose a courageous chairperson and again an outstanding communicator, though she was frequently sniped at for her lack of medical knowledge by a media besotted by medical expertise. Her task and that of NACAIDS was much tougher than that of the Taskforce. Whereas the scientific authority of the Taskforce went relatively undisputed everyone considered themselves experts on education and social questions. Nearly every product of NACAIDS from *Readers Digest* supplements to allegedly pornographic material for use in gay saunas and clubs, from condom caricatures on buses to the notorious Grim Reaper advertisements, were the subject of continuing and often intense controversy.

Relations between the Taskforce and NACAIDS began badly and never fully recovered. On 30 January 1985 the Taskforce issued a press release announcing that on the basis of a sample of homosexual and bisexual men in Sydney it was estimated that between 20,000 and 50,000 men in Sydney carried the virus.²³ There had been no consultation with the sample group, no consultation with the gay community, no consultation with NACAIDS, while the minister read of the story in New York following the hysterical headlines that ensued. As some of the

²³ Taskforce press release, 30 January 1985

gay leaders stated at the time the methodology was ‘shonky’—the sample biased, the extrapolations questionable—and from the beginning I found the figures suspect.²⁴ In hindsight the figures were, of course, much exaggerated. In Sydney seventeen years later the total *cumulative* load of HIV infections was less than half the lowest figure of infections suggested for Sydney in 1984.

But we did not have the advantages of hindsight. What we did have was an angry gay community threatening to discontinue support for research, a chair of NACAIDS commenting tartly on the communications skills of medicos and the chair of the Taskforce exacerbating matters by suggesting the figures were conservative and justifying their release on grounds of the Taskforce’s duty to ‘advise the Australian public’.²⁵ It was not an auspicious beginning to relations between the two national committees. None of this is to argue that the information should not have been published, merely that the extrapolations should have been more thoroughly assessed and those who had to deal with the fallout forewarned.

Relations between the two national committees never really recovered after this unfortunate start and tensions were compounded by the clashing egos of their chairpersons. We had sought to ward this off by having Taskforce representation on NACAIDS but this if anything exacerbated the problems. Undoubtedly the gay representatives on NACAIDS, denied representation on the Taskforce, endeavoured to muscle in on territory which the Taskforce saw as medical/scientific, though the boundaries were perhaps never as clear-cut as some medical scientists assumed. A rather amateurish effort by NACAIDS to develop guidelines for Aboriginal communities incited Penington’s fury and he mobilised State governments and the Commonwealth department of Aboriginal Affairs against it.

But the major clash came over the vexed issue of testing. As a result of an understanding reached with the US administration during my visit to the United States in 1984–85 and through the untiring work of Penington and others, Australia became—in April 1985—the first country in the world to protect its blood banks by providing tests for all donors. But this solution to one problem brought others in its wake. The critical public policy dilemma in HIV testing was the conflict between the community and the individual. It was plainly in the

²⁴ Hence my rather vague reference to the numbers infected in my first ministerial statement to the parliament, Hansard, House of Representatives, 23 May 1985, pp 3083–6

²⁵ The whole imbroglio is well captured in articles in *The Australian*, 1 February 1985, *The Age*, 5 February 1985 and *The Sydney Morning Herald*, 9 February 1985

interests of the community to be able to monitor and assess the spread of the disease. But there was little or no incentive, other than altruistic ones, for the individual to be tested. While there were treatments for the opportunistic infections that characterised AIDS, there was at this time no treatment of any kind for the otherwise healthy person testing positive.

Indeed there were disincentives for testing given the innumerable tales of discrimination, both in Australia and overseas, against those suspected of having the disease. Societal discrimination against homosexuals in general seems to have increased in these years: increased complaints of workplace harassment;²⁶ fears for jobs particularly in the service industries (Ansett and TAA both placed bans briefly on travel by HIV positive people).²⁷ There was also an increase in gay bashings in major cities justified by the plea, ‘we’ve got to stop these buggers from spreading the disease’. If a person was identified as HIV positive the discrimination often became unmanageable—jobs, accommodation, services all denied. The most appalling case of discrimination in Australia was not of a gay but of three-year-old Eve Grafhorst whose ostracism and that of her family finally forced them to take refuge in New Zealand.²⁸

If there was a single imperative driving government policy it was the determination to resolve this dilemma between community and individual by winning the confidence and the cooperation of the affected individuals for policies that would ensure community monitoring and assessment of the disease. This approach ruled out most forms of compulsion. They were never very practicable anyhow. Despite much public clamour to compel the at-risk groups to be tested,²⁹ the at-risk groups—apart perhaps from Haitians—defied any easy identification. This forced advocates of compulsion to favour universal forms of testing. But these tests would have been prohibitively expensive and without any treatment available for the infected would probably have met resistance. Even the compulsory testing for tuberculosis—a frequently cited parallel—was only practised when treatments for the disease became available.

There was some support for the traditional public health approach, insofar as individuals voluntarily undergoing tests should, if positive, be identified to the

²⁶ *The Sydney Morning Herald*, 28 November 1985, an article drawing on the report of the NSW Anti-Discrimination Board; see also article in *The Age*, 14 August 1989

²⁷ Penington, who warned of creating ‘a new class of lepers’, persuaded the companies to drop the bans. See *The Age*, 23, 24 July 1985

²⁸ For a salutary retrospective on the case see *The Australian*, 22 April 1986

²⁹ An October 1985 poll suggested 91 per cent of those surveyed favoured compulsory testing of people suspected of carrying AIDS. Melbourne *Herald Sun*, 2 November 1985

State health authorities for follow-up contact tracing, a practice adopted in Queensland. But would this simply add another disincentive for individuals, inhibiting them from coming forward to be tested, whatever the quality of the confidentiality provisions? As we have seen when New South Wales planned to go down the Queensland path—at least with regard to the notification of individuals³⁰—the bulk of the NSW AIDS specialists opposed it on the grounds that it would discourage testing. The evidence suggests that the modified notification system ultimately introduced in NSW damaged the NSW testing system for a number of years.³¹

Given these constraints it is perhaps not surprising that the clash between NACAIDS and the Taskforce over testing inflated at the time by the media and going down in history as a fundamental division of outlook, was in fact a minor, finely nuanced difference within a framework accepted by all the leading figures. In February 1986 Penington urged all who might be infected to come forward for testing. It was a sentiment with which I agreed, though given that there was no satisfactory fallback position if they did not, I saw it simply as a form of moral suasion. I also thought it unwise that on so sensitive an issue Penington coupled his appeal with deprecating remarks about the safe sex campaign.³²

NACAIDS took an agnostic position leaving the decision on testing to individuals while some of the gay groups were actively opposed. I was unhappy with the NACAIDS view for I thought it desirable that both national bodies should be encouraging the testing of at-risk groups. However, given the sensitivities on the issue, it would have been counter-productive to try and impose my view. I therefore strove for a compromise, which by stressing the centrality of both pre- and post-test counselling, served to encourage confidence in testing procedures. I thought it was a fairly satisfactory compromise but received few thanks from either side.

Finally when talking of ownership there were, of course, the gays, who early staked an ownership claim. They were in many ways quite possessive—it was ‘their disease’. Certainly in the very early years their leadership probably possessed more knowledge about the disease than most other groups in the society, and they were early and persistent advocates of government action.

³⁰ Wran was probably not embarked on a radical alternative policy but was simply posturing to the public. I well remember Penington and I arguing with Wran one spring day against the wisdom of his proposals and the Premier nodding, ‘You’re probably right but they’, gesturing towards the spring crowds in the parklands, ‘want me to do it’.

³¹ *The Australian*, 22 July 1987; *The Sydney Morning Herald*, 27 January 1988

³² *Melbourne Herald Sun*, 12 February 1986

But they were riven by internal conflicts, often over personalities, and were divided between pragmatic compromisers, willing to cooperate with government, and confrontational absolutists, who saw their task as taking on the heterosexual establishment. They were not easy partners for any government.

Partly as a result of my US experience, partly because of the quality and the knowledge of many of their leading figures, but above all because of the policy imperatives outlined above they, and other infected groups, were embraced early and given a real role in the development of policy. So unusual and significant a role was it that, when in 1987-88 the government shifted its educational focus to a greater emphasis on the dangers of heterosexual transmission, exemplified above all by the Grim Reaper campaign, the gays were accused of having, with the acquiescence of the minister, 'hijacked' the agenda thereby turning the disease into a mainstream concern. This charge was levelled by *The Australian*, perhaps the more homophobic of the serious newspapers,³³ by an influential group around *The Age* in Melbourne³⁴ and by the columnist Phillip Adams, obsessed by the importance of anal intercourse in the transmission of the disease.³⁵ These critics questioned the incidence of heterosexual spread in Australia, for which there was not much evidence.

I have little doubt that some astute politicians in the gay community did seek a higher and more general profile for AIDS, recognising that if AIDS was everybody's problem and not just a gay problem it would heighten the pressure on government for money and resources. But the government was responding not to their agenda but to an international agenda. In the period 1987-88 virtually every developed nation shifted its public emphasis from the high-risk groups to the community more generally.³⁶ And the reason for this shift was the accumulating and disturbing evidence of heterosexual transmission in sub-Saharan Africa, highlighted internationally by the Second International AIDS Conference in Paris in mid-1986. While the evidence was partial and there may have well been specific African factors conducive to heterosexual transmission, it would have been irresponsible for the government not to act. Ironically it was the measured Penington, whose concerns were expressed to me personally on his return from the Paris conference, who was instrumental in shifting the emphasis

³³ See remarks by Denis Altman, *The Sydney Morning Herald*, 18 December 1985

³⁴ See the article by Michael Gawenda, *The Age*, 2 May 1987

³⁵ See *The Australian*, 24 December 1988 for a typical article

³⁶ See the comparative studies in Kirp and Bayer, *Aids in the Industrialized Democracies* for numerous examples of these national shifts

of government policy. Later, disappointingly, he was to lend his great authority to the 'gay hijack' canard.

The gay hijacking charge seems therefore parochial and insular, ignoring the international context in which the shift in AIDS education and publicity took place. Not that the charge was without overseas parallels. There was a certain comfort in learning that Mrs Thatcher and her Conservative government in Great Britain were subject to the same accusation for similar policies.³⁸ It was perhaps less believable of the lady with the handbag, than of the ambiguous minister who presided over Australian policies.

Missing from this analysis are some of the more familiar institutions in public policy-making: Cabinet, parliament, and political parties. The explanation is that at the national level AIDS never became a partisan issue, an issue disputed between the major parties. Aware from my American experience of the disfiguring impact on AIDS policy of the partisan debate there, I had from the beginning cultivated influential figures on the Liberal side. These relations were formalised when I responded to a suggestion from James Porter, then shadow Health minister, by setting up an all-party parliamentary liaison committee on AIDS in late 1985. This committee was kept informed on all aspects of the epidemic and regularly briefed by national and international AIDS experts. It acted as a sounding board for government policies and programs, and as a conduit for the concerns of other parties.

Because most of the abler Labor figures tended to be in office, the Liaison Committee, like most such all-party committees, tended to be dominated by the Opposition figures, in this case by the potential ministers, Peter Baume and Chris Puplick. The fact that the maverick Senator Brian Harradine, the parliament's resident moralist, was willing to join the committee meant that many of his genuine concerns over the direction of government policy were handled in the non-confrontational atmosphere of the committee rather than on the floor of the Senate.

The result at the national level was an elite consensus on AIDS policy. Prejudice is always present in any community but it only becomes dangerous to marginalised groups if the prejudices are made respectable by political elites.

³⁷ See Penington in *The Medical Journal of Australia*, 21 September 1987 and *The Advertiser*, 18 August 1988, which provides a good overview of the Taskforce/NACAIDS clash

³⁸ See Virginia Berridge, *AIDS in the United Kingdom, The Making of Policy, 1981–94*, Oxford University Press, pp.75–78, 100–152 and particularly for Mrs Thatcher, p.134. This is an outstanding study of the making of AIDS policy

This did not happen at the national level with AIDS. The national parliament never became the scene of partisan debate on AIDS. Only once was this consensus seriously threatened. At the fourth National Conference on AIDS in Hobart in August 1988 Wilson Tuckey, then shadow Minister for Health, made a provocative and insensitive speech on AIDS and told the prominent AIDS specialist, John Dwyer, that ‘You don’t know what you’re talking about’.³⁹ Momentarily Tuckey threatened to derail the consensus but instead the speech derailed Tuckey. Within a month he was no longer shadow Minister for Health.

I cannot recall a single Cabinet debate on AIDS policy as distinct from AIDS financing. Hawke certainly pushed for the emergency summit of health ministers in November 1984—Neville Wran urged him on—and anyhow there was a federal election in the offing. But his prime ministerial style was to give ministers a free hand in their technical policy areas, only bringing in Cabinet when there were political difficulties or the interests of ministers clashed. AIDS was quarantined from party political controversy and there was little interest among other ministers. I thought it was wise with the help of John Dwyer to take the Prime Minister through the Grim Reaper material—again a federal election was in the offing—and he raised no difficulties. Only on AIDS funding were there prolonged debates—mostly in the Cabinet’s Expenditure Review Committee—and these related more to the overall demands of the Department of Health on the Commonwealth Budget than to the specific amounts for AIDS.

By 1988 the primitive stage of AIDS policy making was over. The outsiders retreat or are absorbed into the governmental bureaucracies or into the medical establishment. Governmental bureaucracies re-assert themselves and the advisory committees are restructured and their influence reduced. With growing knowledge of the aetiology of the disease and with the appearance of treatments for infected people the disease begins to be absorbed into the mainstream practices of Australian health care. Yet it might be hoped that this primitive period left behind a residue of creative approaches in public health that may well be revitalised when the next great challenge confronts the health system.

³⁹ The Canberra Times, 14 August 1988

REVIEWS

Professor Ronald Penny AO

DSc MD BS FRACP FRCPA

In my opening remarks I would like to pay an immense tribute to Neal Blewett's leadership in the AIDS area as well as responding to the honour of the occasion by yet again acknowledging the debt that Australians owe him. He transformed the landscape of response to a new and acute health issue, from the identification of the first case in Australia in 1982 through his timeline to 1988, being the end of the beginning. In Neal's paper and the following three reports you will hear a spectrum of perspectives supporting his position but highlighting different issues, a common feature of historical reports. I would also like to record my enduring respect for Tony Adams, then Chief Medical Officer of NSW Health who at a state level was another powerful force during those primitive years of the AIDS epidemic.

I prefer to think of the AIDS epidemic in Australia using the historical analogy of the Dark Ages, the Renaissance and the age of Enlightenment. As a researcher with a biomedical bias in immunology research as well as heading a clinical and diagnostic immunology service, the first description in 1981 of pneumocystis carinii pneumonia in gay men with immunodeficiency was noted with intense interest. We clearly had a large population of gay men in the inner metropolitan area, with similar socio-demographic characteristics to those reported and felt at St Vincent's that perhaps we may stumble across such a case.

This first patient whom we identified in 1982 and wrote up in *The Medical Journal of Australia* in 1983 was a New York gardener who historically fulfilled the early diagnostic criteria. I was in daily contact by phone with Jim Curran at the Center for Disease Control (CDC) in terms of assessment and treatment. These were indeed the dark ages, without anything more than an epidemiological diagnosis plus evidence of immunodeficiency and pneumocystis carinii pneumonia.

During 1983 David Cooper, a research fellow and staff specialist in the Centre for Immunology, was working in Boston in allergic disorders, which we had identified as our next new research initiative in immunology. I asked him about what his impressions were of AIDS in the United States and whether we should engage in a research commitment in that area. He was strongly supportive of

this initiative and so I set up the Sydney AIDS Study Group with broad representation—Basil Donovan, Rob Finlayson, Julian Gold and David Fox in the Department of Health and key representatives of the gay community.

When the National Institute of Health called for proposals for seroepidemiological research into AIDS, Julian Gold and I prepared an application costing at \$1 million dollars. Unfortunately this was rejected but immediately Tony Adams provided \$50,000 which in those days was still a quite exceptional sum of research money. This allowed us to set up the initial seroepidemiological study which continued for years producing ground-breaking research such as CD4 progression, description of the acute HIV seroconverting illness and many other outcomes from the stored serum and cells, epidemiological and clinical data.

In this Dark Age it was hard as a clinician running a diagnostic immunology laboratory to grasp the research potential of this new, emerging, unknown disease without any understanding of its clinical and diagnostic spectrum or causation.

Being involved in state and Commonwealth policy-setting roles, it was also very difficult from both the public and professional perspective to convey the pressure to manage fear, anxiety and misinformation about a disease that combined the potent mix of death, sex and drugs. My own review will in part contrast with that of Neal Blewett.

I want to divide my discussion into the Commonwealth response, the states' response (mainly NSW), and that of the professions—the community, legal and the media, and finally suggest what are some of the key lessons learnt from this period. I agree with Neal's view that much of the policy was formulated within the context of a gross lack of data, gross lack of knowledge and a gross excess of public, political and fringe lunatic pressure. All of this affecting a community potentially at grave risk of a devastating disease, a community that was already marginalised, subjected to gross discrimination and which itself, in the beginning, was politically divided.

The Commonwealth

In 1983 a working party of the National Health and Medical Research Council (NHMRC) was formed, chaired by David Penington and including Julian Gold, Bob Beale from the Blood Transfusion Service, Ian Gust and myself. This was soon followed by the AIDS Task Force, which with relatively few cases began its task of crafting a national response. This should be contrasted with the situation

in the United States, which by the time of the international conference in 1985 had experienced more than 500 deaths. The word AIDS had not been mentioned by President Reagan and it was left to the then Vice-President George Bush to make the first plaintive remarks. The AIDS Task Force, with an expanded committee of professionals but excluding membership of the affected community, addressed policies such as medical treatment, laboratory testing, collection and review of epidemiological data. Once a diagnostic test was available, Australia became the first country to establish testing of the blood supply, triggered of course by the four transfusion cases in children in Queensland. State differences became a major issue for the committee in terms of the legal status of male-to-male sex in NSW compared with legalisation in NSW. As outlined in Neal Blewett's paper, NSW policy on compulsory notification by name in 1985 was a blow to the principles of voluntary testing and contact-tracing, principles enunciated by professionals and community alike. David Cooper, Julian Gold and myself had an unsuccessful meeting with Neville Wran to try to dissuade him from this course of action.

Establishing the Task Force without gay community representation was an unfortunate and flawed policy, but it was not only the Queensland government that refused to include gay community representation. This led to the establishment of the National Advisory Committee on AIDS (NACAIDS) headed by Ita Buttrose whose focus was public and targetted community-based education programs. From my recollection I was the only person present on both the AIDS Task Force and NACAIDS—which at least provided some continuity and flow of information in both directions. On the whole the two committees failed to work collaboratively and ultimately in 1988 were replaced by the Australian National Council on AIDS headed by Peter Karmel, an educator but with no expertise in AIDS.

NACAIDS was responsible for the now famous—or infamous—Grim Reaper campaign, the Beds and Feet campaign, and many other public education programs. Beds and Feet was a remarkably interesting exercise in media management. The producers of the media campaign wanted to include beds with same-sex couples—the message with respect to HIV being 'you are who you have slept with'. The Federation of Australian Commercial Television Stations (FACTS) refused to have the ads released in that setting. In the end the problem was overcome by locating beds with same-sex couples in such a way that they could not readily be seen on the television screen. In her own way Ita related very effectively to the general community, and especially empathetically to the

gay community who had been so unfairly excluded from the AIDS Task Force. I must add that this exclusion was in no way a reflection of Neal's position but rather the result of external and AIDS Task Force pressures.

Another valuable and powerful political initiative engineered by Neal was to establish a Commonwealth Parliamentary Committee of an all-party persuasion to generate broader bipartisan support. This was in the main a highly successful way of engendering debate within the committee, in preference to the public domain. Wilson Tuckey remained the exception in this respect, as reported by Neal Blewett.

State

In the NSW Health Department's AIDS Committee, the problems of the AIDS Task Force were certainly not reproduced in terms of membership and representation. Apart from the usual suspects in those early days of Julian Gold, Alex Wodak and myself the committee included social scientists from Macquarie University, Bill Whittaker and others. With the introduction of compulsory notification, the NSW Health Department established the Albion Street Clinic as an anonymous testing site requiring only initials and date of birth. Many of the initial clients of the Albion Street Clinic provided the name of Neville Wran. From the multiple parties representing different sectors and interests of the gay community, the AIDS Council of NSW (ACON) was eventually formed which in NSW played an outstanding role. With the advent of diagnostic HIV testing, NSW established multiple sites of public health laboratories for HIV and T-cell testing, initially an inpatient ward of six beds at St Vincent's Hospital, eventually providing up to 24 and additional sites at Prince Henry, Royal Prince Alfred and Westmead hospitals. Again, successive NSW Premiers and Health Ministers, and Nick Greiner as leader of the Opposition, supported a bipartisan approach. Most of the political dissidents in the bipartisan area, in particular Fred Nile and Rosemary Foot were generally successfully marginalised from influence and policy setting.

Professions

The appearance of a new epidemic saw many clinicians make sideways moves using their specific expertise. Immunologists such as David Cooper, Graeme Stewart and others, virologists from Prince Henry and Westmead in particular, infectious disease specialists and the multitude of doctors working in sexual health, adapted their skills and expertise in the field of research, clinical and diagnostic testing toward this new disease. The medical profession lobby however, led at that time by Bruce Shepherd of the AMA, provided a fairly heavy assault on HIV, particularly in terms of the risks to surgeons and general

practitioners all in fear of contagion of HIV by known and even unknown modes. There were however significant elements of sanity such as Dick West from Royal Prince Alfred hospital who chaired an Infection Control Committee of the Royal Australasian College of Surgeons, of which I was a member, which brought forward sensible strategies for the management of surgical patients. Although occurring after the ‘primitive years’ or ‘Dark Ages’ of the AIDS epidemic, the transmission of HIV to five women in a surgical office/practice in the Eastern Suburbs had a profound impact, as did the issue of transmission through needle-stick injuries to health care workers. In spite of this an astonishing number of doctors—in the hundreds—wished to have their skills in the management of HIV and the prescribing of antiretrovirals upgraded. Sue Morey as Chief Health Officer of the time is to be congratulated for supporting this initiative, which originated from the NSW Ministerial Advisory Committee on AIDS, of which I was chair at the time.

Community

I have already referred to the effective role that ACON played, which will be amplified I am sure by Lou McCallum, but I would like to refer to the Australian Federation of AIDS Organisations (AFAO), which is the overarching umbrella organisation federally. With membership first on NACAIDS and then on ANCA, AFAO played a remarkable role. Australia in general and NSW in particular owes a debt to the powerful influence on confidentiality, privacy, and anti-discrimination laws which arose as a result of community-based advocacy. Injecting drug users generally were not as well organised with regard to a community role. I chaired the National Committee advising on injecting drug use that held its first workshop in 1989. This workshop occurred three-and-a-half years after Alex Wodak introduced needle and syringe exchange programs at the state level which set NSW on a major harm-reduction program with needle and syringe exchange and safe disposal programs, expanded methadone programs, education strategies in conjunction with the NSW Injecting Drug Users Association, which were eventually adopted by the Commonwealth.

Due to a major conflict in NSW between the views of the NSW Departments of Health and Corrective Services in relation to methadone in prisons, I was asked by the then Premier, Nick Greiner, to chair the NSW Prison Medical Service to address a far broader range of health service related issues than methadone alone. This allowed the opportunity to introduce a range of major public health policy issues to a service providing a range of initiatives to a population at risk of blood-borne infections and to the Indigenous population.

Legal issues

I have already referred to the anti-discrimination laws but I would like to restate that at the beginning of the AIDS epidemic in 1982, confidentiality and privacy issues were hardly practised in the health system or were at best poorly observed. Continuing pressure resulting from discrimination against minority groups over issues of employment, education and health servicing meant that finding a balance between the rights of the public health authorities and the rights of the individuals became a very important battleground. I was particularly sensitive to these issues and felt they had to be hard fought and were eventually successfully won. Laws were changed also with regard to injecting drug use in NSW, which allowed the carrying of paraphernalia but not the actual drug injection—clearly an anomaly but overall it was successfully managed in NSW at least.

The media

The media was clearly impossible at the onset of the AIDS epidemic. Everyone was an expert, especially shock jocks and media heads, expounding new and more remarkable ideas. Communicating sense in managing the AIDS epidemic, and more importantly its modes of transmission, were a heavy time pressure for those involved in handling the almost daily manifestos from the so-called experts or responding to new theories or discoveries from overseas. In spite of that the 1980s saw the socialisation of condoms, acceptance of needle and syringe exchange programs and the sealing off of many of the avenues that had existed for those wishing to push the homophobic discrimination barrow.

So, what are the lessons that I personally have learned from the AIDS epidemic? Perhaps the most important one is to guarantee partnership, consultation and engagement between government, professionals and the community. Political leadership should try as much as possible to avoid politicising health issues. I feel that experts discussing issues may produce controversy on the issues but not result in political controversy itself, which often paralyses sensible actions.

Policies, when being developed, should have the ‘5-r’ test applied: they should be **r**epresentative, **r**ational, **r**esponsible, **r**esponsive and **r**apid. The media can play profoundly valuable roles in disseminating sensible and timely information, as I believe it has done in the SARS epidemic with which I have also been involved. Sense and sensibility on the part of the media were hard to find during the early days of the AIDS epidemic. The media information model is usually confrontational, or ratings-based, and therefore places greater emphasis on ‘fringe’ views.

Postscript

In 1990 I resigned from the Commonwealth ANCA Committee due to the appointment of a Health Minister with little interest in AIDS and influenced, post-Neal Blewett, by a bureaucracy which at that time was interested in control without an adequate high-level skills base in this incredibly delicate area, and which represented a new policy vacuum. The formation of the First National Strategy in 1989 was a landmark, but with Neal Blewett leaving the Health Ministry the Commonwealth leadership role temporarily evaporated in the AIDS area. I personally had more satisfaction in the service focus of health policy in NSW, which was more empathetic at ministerial level, and with one of the best departmental health agencies I ever worked with—the NSW AIDS Bureau, directed in succession by Ruth Cotton, David Lowe, Ross O’Donoughue and Chief Health Officers Sue Morey and George Rubin.

Thank you for the opportunity to reflect on these early years of my public health activity.

Mr Lou McCallum

This review, like the work that it is reviewing, is mainly a personal reflection on the early days of AIDS policy in Australia. I am writing it in southern India, without access to any documents or other formal records of events, so my apologies in advance if it lacks chronological accuracy.

I am a gay man and have been working in the AIDS epidemic in Australia since the beginning. I have occupied many roles, from volunteer tea person at the St Vincent's AIDS clinic in Sydney in early 1984 to Executive Director of the Australian Federation of AIDS Organisations in 1996. I am currently an AIDS consultant in Asia and the Pacific, working mainly with non-government organizations (NGOs) on community care and support programs.

Reading Dr Blewett's paper stirs up many feelings for me. Not only have I worked in this epidemic for what seems to have been most of my adult life, I have lived through it, losing many great friends along the way and seeing enormous changes in the community in which I live. The most interesting thing for me about reviewing Dr Blewett's paper is to see how strikingly different things can appear, depending on your own perspective and on what role you are required to play.

When the 'gay disease' was first talked about in Sydney I was working as an oncology nurse at the Prince of Wales Children's Hospital in Randwick and was also volunteer training coordinator for the Gay Counselling Service. I remember speaking at a gay community meeting at Paddington Town Hall, calling for people to come forward to be trained as community carers. This was before the first person had been diagnosed in Australia, but we were in close contact with the gay community in San Francisco and it seemed inevitable that we would be affected.

When the first people with AIDS started presenting at St Vincent's Hospital, I was called in, along with the Rev Jim Dykes from the Metropolitan Community Church and Terry Goulden of the Gay Counselling Service, to provide volunteer counselling to the people who were being diagnosed. The three of us would attend the Friday ward meeting and would be assigned new patients to visit and support. If they were lucky enough to get out of hospital, we would follow up with home visits.

Looking back, this was a very brave and unusual act of trust by people like David Cooper, Ron Penny and the other doctors at St Vincent's. It was unusual to

have lay people involved in ward rounds, to allocate them a case load and to include them as legitimate members of the care team. This sharing of power and responsibility between doctors and community members has been a key feature of the AIDS response in Australia and is still quite rare in other areas of health practice in my experience. These were terrible days: young men came in desperately ill and often died very quickly; families were in turmoil as they were summoned from all over Australia to the bedsides of their critically ill sons, often meeting their son's lover for the first time; wives were finding out that their husbands were bisexual.

In the face of all this adversity, we developed strong friendships within the care team and a respect for each other that established a firm foundation for the partnership response. This is striking to me. As a community member, and later a community 'bureaucrat', I think that the relationships I developed at that time with doctors, nurses, health officials and others, by working alongside them in difficult times, were extremely valuable.

This is perhaps why I developed into what Dr Blewett refers to as a 'pragmatic compromiser' rather than a 'confrontational absolutist'. It was always difficult for me to position those people I had worked with so closely as 'enemies of the gay community', even when I disagreed with some of their views.

In those early days, the clinic and ward at St Vincent's were the epicentre of the epidemic and I recall developing very constructive relationships with the state health bureaucrats—people like Geoff Brandon and David Lowe from the Health Department seemed to come to the clinic and the ward in order to consult with people about the situation. David, particularly, had come from the Anti-Discrimination Board and had earlier been a board member of the newly established AIDS Council of NSW, so this helped in the establishment of a sensible partnership at state level. I also remember a stream of politicians visiting the ward and the clinic to get some sense of what was going on. One shadow federal Health Minister fainted in the corridor and had to be carried out.

When the antibody test became available, I took up a position as a part-time counsellor at the Albion Street Clinic and continued my voluntary work at St Vincent's. As Dr Blewett points out, there was certainly a lot of debate in the gay community about testing. On one side there were people within the AIDS Council warning about the discrimination that would result from testing and, on the other side, people like the Reverend Jim Dykes publicly calling for people to come forward and be tested.

This was not such a great issue for me as a counsellor in the testing clinic and I am not sure to what degree government policy actually set back the public health response in New South Wales. Plenty of gay men came to be tested. They only had to give a first name and two letters of a surname and a date of birth, and many gave false information. We encouraged this, as long as they gave the same false information every time so that the total number would be reasonably accurate. Gay men came streaming down from Queensland, up from the ACT and from other places that had less pragmatic policies. For me, this demonstrated that people would make up their own minds about things and that a strong stand taken by the community organisations didn't always result in compliance by community members. We had, after all, been struggling for freedom for many years and were unlikely to submit to a new set of rules put in place by gay 'community leaders'.

It was around this time that AIDS councils were being established in the States and Territories and that the Australian Federation of AIDS Organisations (AFAO), the national AIDS NGO, was established. In NSW the AIDS Council quickly became a key player in the response. I remember brave and explicit campaigns like the *Safe Sex Summer*, and an informal policy and advocacy tactics group called *The Tennis Club*.

Many of us had been involved in the gay rights movement and were familiar with this sort of advocacy—using our networks to find out who could influence people in key positions. We had another strategy as well—putting people from the gay community into positions within the bureaucracies, both at national and at state level, to make sure that our voice was heard in the many corridors of power. I am not sure that I agree with Dr Blewett's analysis of the health bureaucracies at the time. I worked closely with people from the AIDS bureaux in the Commonwealth, New South Wales and Victorian Health Departments and found many talented and innovative people. Mary Scott, Helen Evans, David Lowe, Ruth Cotton, Rob Moodie and Phil Carswell all stand out in my mind as early crusaders. They had difficult roles to play, developing partnerships with community organisations and service providers that were unusual in the departments they worked in and they must have spent a lot of time out on a limb. The models of partnership that they created have been attempted in some other areas of health. Mental health is perhaps the best example.

The advantage that the community sector had at this time was that we had the resources to contribute to policy development. We had people who could

generate sensible policy discussion papers. We could quickly translate complex policy issues into clear information for our communities (not just gay but intravenous drug user (IDU), sex worker and people living with HIV groups) and could communicate their views quickly back to government. This was a very powerful strategy. We could speak with some authority about the views of the affected communities. It helped the bureaucrats and politicians to defend the positions they were taking against the criticism of their peers. The restriction of the membership of the national AIDS NGO to State and Territory AIDS Councils and the national PLWHA, sex worker and IDU organisations meant that it was relatively simple to quickly canvas membership opinion on an issue and make sensible inputs in decision-making committees and in the press. Other health NGOs I have been involved in since this time have had a much broader membership and have found it difficult to come to a consensus view on key policy issues, weakening their influence in the policy debate.

We also had good links with the social researchers, particularly with people like Sue Kippax and Garry Dowsett at Macquarie University. This allowed us to generate the evidence we needed to support the health promotion strategies we were using.

At a national level, AFAO's policy team grew from one to five full-time staff members, giving it a distinct advantage over the AIDS unit in the Commonwealth Health Department, whose staff was primarily involved in project management of a range of large, medium and small grants. I have not seen this model repeated in other areas of health policy. For instance, the Consumers Health Forum, the NGO responsible for advocating at a national level on behalf of all health consumers, does not have a dedicated, government-funded policy position. The Australian Hepatitis Council has also not been provided with this kind of resource. This significant investment by government in the development and analysis of AIDS policy at community level set the AIDS response apart and led to a particular type of participation.

Dr Blewett divides the community lobbyists into 'pragmatic compromisers' and 'confrontational absolutists'. It is true to say that there was often conflict within the sector about whether to compromise or to stand firm. Sometimes we used this to our advantage. A community bureaucrat like me would be sent in to negotiate a way forward. Politicians and bureaucrats feared the direct-action approach of ACT-UP and NAPWA and often preferred to use people like me as intermediaries. I would tell them that they had better work out a solution with me

because I could not tell how long I could keep my ‘absolutist’ colleagues at bay. To be honest, I am not sure whether it would always have been possible to mobilise the community to speak with one voice, but the threat was often enough to bring about a negotiated solution.

This lobbying tactic did not always work. Community bureaucrats like me were often the targets of the ‘absolutists’, who thought we had been captured by the bureaucracy and had become too conservative, trading too much away. The role of intermediary was often quite fraught as a result. In referring only to conflict within the community sector and the difficult nature of the partnership with community, I think Dr Blewett seriously understates the contribution community organisations made to the early AIDS response in Australia.

The availability of the HIV antibody test saw the emergence of a new force—the movement of people living with HIV/AIDS. My first recollection of this as a public movement was when people with HIV came up and stood on the stage at the closing session of the national AIDS conference in Hobart, led by people like Andrew Morgan and Terry Giblett. This seemed to me to be a defining moment and sparked the beginning of the emergence of the ‘HIV community’.

It was around this time that the federal government commissioned Elizabeth Reid to develop a discussion paper on national AIDS policy. This was my first encounter with national policy development. A group of AIDS counsellors from around the country had begun to communicate with each other and had formed a national organisation as a way of sharing ideas. Elizabeth consulted with us in the lead-up to the development of the first national strategy and I remember being struck at the time by the fact that those front-line health workers could actually have a voice in national policy development. I had never seen this kind of access to policy-making as an oncology nurse. I suspect that many people in the health system still do not see this kind of direct access to the formulation of national policy.

The position paper developed by Elizabeth was the first to clearly use the language of partnership—a feature of the AIDS response in Australia that has endured to this day. It is amazing how powerful that language has been for us. It prescribes a set of values: fairness, mutual respect, the sharing of power, honesty and transparency. Whenever we had difficulties in our relationship with government or with the health system we could use the word ‘partnership’ and the values it suggests as way to stake our claim for a better hearing. For me it has been the most powerful tool that we have had.

The notion of partnership, combined with the existence of a national strategy that not only clearly set out roles and policy, but also allocated funds, became the core of the response. Defining a clear role for the community sector at national and at state and territory level, with guaranteed funding, meant that we in the community could get on with the tasks we were allocated. It meant that, even though we were working in partnership with other sectors, we had some distinct turf and legitimacy as distinct partners at the decision-making table. It also meant that we could speak with some authority on issues relating to the communities at risk and that, in this area, our opinion carried more weight than other partners.

This raises for me the whole question of community participation in health. Some unusual circumstances led to this power sharing by government and the medical profession. The AIDS epidemic in Australia was localised within three marginalised groups—gay men, injecting drug users and sex workers. People in these groups were committing illegal acts in most states and territories. They were seen as ‘hard to reach’ and not likely to respond to health messages generated by government. There was also a fear that the epidemic would move from these so-called marginalised groups into what people called ‘the general community’. The gay community, within which most of the victims of the epidemic lived, was seen as containing some skilled people who could assist in the response.

Some argued at the time that government should simply let the epidemic ‘burn itself out’ in these marginalised communities. Others argued, more persuasively, that this would not happen, that there were bridges from these marginalised communities to the general community—bisexual men, clients of sex workers, partners of drug users. So the partnership was struck.

This fear of the crossover of an illness into the general community, combined with a belief that the best way into marginalised communities was through their own organisations, led to the sustained government investment in the community response to AIDS. But government has not replicated this model in other areas of policy. The Hepatitis C response has struggled along, wrongly labelled at national policy level as an AIDS-related disease’ for many years, and has not been provided with a clear policy, stable resources and distinct roles for the community.

The word ‘partnership’ has been used in many areas of national health policy since the relative success of the AIDS partnership, but the partnerships that are developed rarely contain the sort of power and resource sharing that was seen in

the AIDS response. They rarely involve dedicated and stable funds flowing to community organisations.

Dr Blewett points out, quite correctly, that the bipartisan nature of the response at national level kept national politics out of AIDS to a great extent. This was perhaps a sign of the times. The response was set up under a national Labor government and Labor governments have traditionally supported the role of NGOs in policy development and program implementation. Australia has now had a conservative government at national level for almost a decade. This has meant significant changes in the community sector, particularly in the area of health. Many organisations that have disagreed with federal Liberal government health policy have either lost their funding or have had their resources significantly trimmed. Some of this has been done under the guise of competition policy. Consumers' Health Forum, for instance, lost a significant proportion of its government funding for challenging the private health insurance rebate. The Public Health Association lost all of its government funding for fighting the erosion of public health services.

Rather than allowing NGOs to pursue their own policy and advocacy goals, the Howard Government has tended to purchase a set of narrow products from NGOs, and increasingly from private consultants and consortia. To a large extent in health administration these days, government decides what products it wants to purchase and who it will purchase them from. This is a significant shift in power and often leaves NGOs trying to decide whether the policy gag that now comes with receiving national government funding is worth the price. The AIDS NGOs appear to have been less affected by this shift than other health NGOs, though I suspect this would change if they needed to directly challenge a key area of government policy. I am also not arguing that a change in national government would necessarily see a shift back to the old days of strong NGO health advocacy. Times have changed significantly on all sides of national politics in Australia since the early days of the AIDS epidemic.

In closing, I am pleased to have been given this opportunity to reflect on the impact of AIDS policy on other areas of health policy. I think it is very timely. In my work as an AIDS consultant in Asia and the Pacific region I see the direct impact of the increased privatisation of health services in the countries I work in. I see the gap between the rich and the poor widening in these countries, as it is in my own, and I wonder how we can expect to improve the health of nations and communities under these circumstances.

Dr. John Ballard

Australian National University

Dr Blewett's paper opens with the statement that his is 'a hybrid work—part personal memoir, part public policy essay and part political science analysis'. Since it is difficult to out-guess the Minister on his personal account—and indeed his memoir is candid, balanced and stylish, as expected—my comments are concerned primarily with his essay as an analysis of public policy.

AIDS is peculiarly interesting as a policy issue since, as Blewett indicates, there were no germane precedents for its consideration, and information in the early years was partial and conflicting. There were thus no obvious 'owners' and the Minister, within the limitations that he suggests, was in an exceptional position to shape an Australian response.

There were, however, structural factors beyond federalism that set the conditions of possibility for a policy response. First, the initial conceptualisation of AIDS as an issue concerning blood control was one that fitted Australian blood arrangements in such a way as to require and to enable immediate political intervention. Second, the timing of the arrival of AIDS found Australia with a well established concept of health promotion and a mobilised community of those most affected by AIDS, neither of them available in Australia a few years earlier, and neither of them available in the mid-1980s in countries such as France, significantly inhibiting their policy response.⁴⁰

Following the UK model, blood collection became a monopoly of the Red Cross in Australia and was financed jointly by the Commonwealth and state governments. In addition, Factor VIII for haemophilia was produced exclusively by the Commonwealth Serum Laboratories. Thus blood control was widely seen as a matter of government responsibility in Australia in ways that it was not in countries where blood is commercially collected or imported.

In addition the close links between Australian and US medical communities meant that, once viral transmission was identified as responsible for AIDS and diagnostic tests were quickly developed after April 1984, Australians were among the first outside the US to identify cases of viral transmission through

⁴⁰ I have developed this interpretation in a more theoretical setting in 'The Constitution of AIDS in Australia: taking "government at a distance" seriously', in Mitchell Dean and Barry Hindess, eds, *Governing Australia: Studies in Contemporary Rationalities of Government* Melbourne: Cambridge University Press, 1998, pp 125–38

blood transfusion. A virologist from Melbourne's Fairfield Hospital spent his sabbatical leave at the Centres for Disease Control during the crucial second half of 1984 and relayed home the rapid developments in thinking about blood transmission; he was the only foreigner at the CDC interested in AIDS. With access to viral antigen from CDC, Fairfield was able to find in mid-October that one-third of stored sera samples from Australian haemophilia sufferers who had received Factor VIII were viral antibody-positive.

While the Fairfield discovery aroused the first anxious concern with AIDS in the Commonwealth Department of Health, this was not a public matter. Access to testing, however, was essential for identifying the virus as the source of the Queensland babies' deaths announced a month later, in the midst of a federal election campaign; this, as Blewett indicates, was what touched off the first spate of national policy choices. In no other country did blood play a central role in requiring political intervention on AIDS and this, in part, explains the delay until mid- to late 1986 in national AIDS policy elaboration elsewhere.⁴¹

What were the levers that government in Australia had at its disposal for dealing with AIDS? The Blewett account stresses the roles of the AIDS Task Force under David Penington and NACAIDS under Ita Buttrose, and the importance of the medical specialists who worked on AIDS. It gives short shrift to the Commonwealth Department of Health but, intriguingly, does not mention the restructuring which the Minister put in place at the end of 1984. This brought to the fore specialists in public health who had made their careers in health promotion through community involvement.

Health promotion as an ideology had made a more substantial impact in Australia than elsewhere, particularly through the perceived success of initial tobacco control campaigns. Several of the Commonwealth and state health officials who had a shaping influence on AIDS policy and practice were leaders of what was effectively a social movement within the health community. One of these was the Director of Health Promotion in Victoria who, early in 1985, argued that the only specialists in gay health and AIDS education were the Victorian AIDS Council established by the Melbourne gay community. Linda Stephens employed two of its leading figures and funded initiatives of the Council, which had been following US medical developments more closely than all but a very few doctors

⁴¹ For a comparative analysis of the impact of blood control on AIDS policy, see Eric A Feldman and Ronald Bayer, eds, *Blood Feuds: AIDS, Blood, and the Politics of Medical Disaster* New York and Oxford: Oxford University Press, 1999, where I provide further detail on the Australian experience.

and which set the pattern for safe sex campaigns during the first year. The new AIDS Coordinating Unit, located in the new Health Promotion Division of the Commonwealth Department, seized on the Victorian precedent and promoted it in other states—a case of policy-making from below.

The presence of an alternative approach to public health with a strong constituency within the medical profession and both Commonwealth and state departments provided broad legitimisation for the Minister in his opposition to the traditional methods of surveillance—compulsory testing, notification, contact-tracing and quarantine. These were the central features of the Queensland approach, but they also appeared in Penington's early proposal to close the gay bathhouses and his consistent promotion of testing by the states, e.g., among Aboriginal communities, as well as the AMA's later demand for the testing of surgical patients.

The existence of well-mobilised gay communities in Australian cities is taken for granted, but they are largely products of the years immediately prior to the onset of AIDS. As the Minister points out, the legislative battles over decriminalisation in some states were still being fought and they helped to traumatise and divide the Sydney community, leaving much of the early innovative activity on AIDS policy to the Victorian AIDS Council (VAC). It is arguable that Adam Carr of VAC, through his monthly articles in *Outrage* during 1984 on the progress of scientific thinking about AIDS and its implications, saved more lives than all later education campaigns. VAC was responsible for framing much of education policy on HIV, articulating safe sex practices as a form of ethical citizenship; this was later validated by epidemiological cohort studies. It also came up with a proposal for the first of a series of national conferences on AIDS; taken over by the Commonwealth these provided significant occasions for policy discussion.

The Councils were largely responsible for developing community care programs in collaboration with clinics and hospitals. Leaders within the AIDS Council of NSW took the initiative in seeking out researchers at Macquarie University to establish the first social research projects on AIDS, projects which set world standards on community collaboration in the design and execution of research and the rapid implementation of findings. Several developments in AIDS education policy flowed from the Macquarie projects.

The presence of a mobilised health promotion ideology and of coherent and mobilised gay communities were thus essential as sources of innovation in the

Australian policy response. They are perhaps taken too readily as facts of life in Australia rather than seen as prerequisites for constructive AIDS policy, which were absent elsewhere.

It is no derogation from the Minister's crucial importance in making a set of broad policy choices to recognise these prerequisites as well as the importance of staff who had much of the carriage of policy construction. The Minister's office and the new AIDS Coordinating Unit in the Department played critical roles in structuring policy choices by the minister and his state counterparts. Here Bill Bowtell, the Minister's imaginative and aggressive chief of staff, was in a central position. Bowtell was in close communication with the AIDS Councils and medical specialists during the early formative period of 1983–84. He organised the ministerial meeting of November 1984 and suggested the shape of NACAIDS and the AIDS Coordinating Unit, which he in effect directed. When he was replaced at the end of 1985 by a chief of staff who was determined to give the Minister a lower and less vulnerable profile on AIDS, Bowtell retained a strong voice in the shaping of education policy and The Grim Reaper campaign. He was seen by Penington as his chief opponent in gaining the Minister's support and their antagonism was reflected in Penington's carefully timed attack on Blewett's advisers, which won headlines on election day in 1987.⁴²

Returning to Dr Blewett's aim to provide both memoir and policy analysis, it may be impossible to straddle both if policy is read more broadly than ministerial activity. Much innovation in AIDS education and care, as well as needle and syringe distribution programs in Sydney and Canberra, for which Australian AIDS policy in the primitive years became an international model, did not fall within, nor necessarily derive from, the Commonwealth Minister's policy settings. While the Minister developed a broad policy umbrella under which innovation could take place, he also drew much of the legitimation for his approach from the success of community and state initiatives.

⁴² *The Sydney Morning Herald*, 11 July 1987