

# 1. The 'Homosexual Cancer': AIDS = gay

Reports about a lethal mystery disease began trickling into mainstream Australian media by mid-1982, some months before the first Australian case would be diagnosed. The reports told of an increasing number of unexplainable cases of Kaposi's sarcoma and pneumocystis carinii pneumonia (PCP) among young gay men in America. Both these illnesses are relatively rare and indicative of problems with the body's immune system. What doctors could not explain was why so many previously healthy young men were presenting with damaged immune systems. They also could not explain why nearly all these young men seemed to be gay.<sup>1</sup>

Before HIV was identified as the virus leading to AIDS, a number of theories pointed to a causal link between homosexuality and AIDS. For example, the 'overload theory' suggested that the gay lifestyle, including a combination of drug use, poor health and a history of sexually transmitted infections, led to a collapsed immune system.<sup>2</sup> Similarly, a report in the *Launceston Examiner* in 1982 explained that researchers were 'studying the effects of drugs used by homosexuals to enhance orgasm, and have examined the possibility that frequent bouts of venereal disease among homosexuals might break down the body's ability to fight illness'.<sup>3</sup> In the absence of any information beyond an observed link between immune system problems and gay men, researchers began using the term 'GRID' (Gay Related Immune Deficiency) to describe the appearance of Kaposi's sarcoma and other infections among this population group. The media followed suit, coining a number of terms including 'the homosexual cancer' and 'the gay plague'. Even when the clinical diagnosis of HIV was made, and people became aware that the virus could also be spread through heterosexual sex, the perception that there was an intrinsic link between homosexuality and AIDS tended to persevere in Western countries.<sup>4</sup>

The accepted beliefs about AIDS in the early 1980s, before HIV was discovered, were that it was contagious and deadly. This merged with existing homophobic attitudes to produce an image of gay men as diseased and dangerous—guilty not only of misdirected sexual predilections but of their newfound potential to infect and kill 'normal' Australians. All gay men came to be seen as potentially

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1 Kraft, Scott 1982, 'New Illness Strikes Gays', *Launceston Examiner*, 13 July, p. 6; Chadwick, Paul 1982, 'States Warned of Mystery Killer Disease', *The Age*, 20 July, p. 16.

2 Seidman, Steven 2002, 'AIDS and the Discursive Construction of Homosexuality', in Kim Phillips and Barry Reay (eds), *Sexualities in History: A Reader*, Routledge, New York.

3 Kraft, 1982, p. 6.

4 Seidman, 2002; Watney, Simon 1994, *Practices of Freedom*, Rivers Oram Press, London.

contagious and deadly.<sup>5</sup> As Gary Dowsett has written: 'It is almost as if gay men were the virus and that they, rather than it, caused the pandemic.'<sup>6</sup> Steven Seidman agrees, arguing that the response to HIV/AIDS in Western society was structured by homophobia.

All diseases, particularly those that are communicable, lend themselves to some degree of moral interpretation: leprosy, for example, has long been associated with poverty and lack of hygiene and syphilis has been linked to prostitution, adultery and other behaviour considered 'immoral'. It is not difficult to understand how AIDS brought with it the potential to create a new social foothold for homophobia and why people feared it could become the basis of renewed calls for the punishment of homosexuality.<sup>7</sup> From the outset, AIDS was directly associated with a sexuality and lifestyle already subject to social stigma, disapproval and, in many places, illegality.

In October 1989, *The Bulletin* magazine published a cover story on homosexuality, discussing increasing reports of acts of discrimination against gay men and lesbians in the wake of AIDS. The article observed that the new awareness and tolerance of homosexuality that had been developing since the 1960s were giving way to increasing reports of anti-homosexual violence in the major Australian cities: 'Public ignorance associated with AIDS is believed to have had much to do with the slide back into the fear and loathing of the '50s when all queers, poofers and dykes were regarded as fair game.'<sup>8</sup>

There is some evidence to support this statement. For instance, in 1985, the two major Australian airlines—Ansett and TAA—imposed a ban on all HIV-positive passengers. Although short-lived, the ban came alongside increased complaints of workplace harassment and fears that gay men could be banned from jobs in the service industries. There were also increasing reports of gay bashings in major cities and indications that the public supported compulsory detention of gay men.<sup>9</sup> A survey conducted by the National Centre for Epidemiology and Population Health in 1991 found respondents felt more sympathy for people who died as a result of excessive alcohol or tobacco consumption than for gay

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5 Seidman, 2002.

6 Dowsett, Gary 1998, 'Pink Conspiracies: Australia's Gay Communities and National HIV/AIDS Policies, 1983–1996', in Anna Yeatman (ed.), *Activism and the Policy Process*, Allen & Unwin, Sydney, p. 173.

7 Pereira, Darryl 1999, 'HIV/AIDS and its "Willing Executioners": The Impact of Discrimination', *Murdoch University Electronic Journal of Law*, 6(4), <<http://www.murdoch.edu.au/elaw/issues/v6n4/pereira64nf.html>>

8 Stannard, Bruce and Murphy, Kevin 1989, 'More Than a Million Australians? Still Glad to be Gay?', *The Bulletin*, 10 October, p. 50.

9 Wilson, Paul, Walker, John and Mukherjee, Satyanshu 1986, *How the Public Sees Crime: An Australian Survey*, Trends and Issues in Australian Crime and Criminal Reporting Series No. 2, Australian Institute of Criminology, Canberra; Synnott, John 1985, 'Board Blames Hysteria for Gay Sackings', *Illawarra Mercury*, 1 August, p. 5; Steven Mark, Lawyer and President, NSW Anti-Discrimination Board, Interview with Diana Ritch, 12 August 1993, Oral History Project: The Australian Response to AIDS, TRC 2815/52, National Library of Australia, Canberra [hereinafter NLA].

men who died from AIDS.<sup>10</sup> By the early 1990s, approximately 20 per cent of complaints regarding homosexual discrimination put to the NSW Anti-Discrimination Board contained some element of HIV or AIDS discrimination.<sup>11</sup>

Internationally, there were reports that fear of AIDS was leading to overt acts of discrimination against gay men and lesbians. In 1983, New York City Council established an AIDS Discrimination Unit within the city's Commission on Human Rights. The unit recorded numerous complaints from healthy gay men and lesbians who had been fired from their jobs or thrown out of their homes on the basis of allegedly being 'AIDS carriers'.<sup>12</sup>

A study conducted in the early 1990s on HIV/AIDS-related discrimination in Australia found that people tended to justify their prejudice towards HIV-positive people because they assumed people with HIV/AIDS were likely to have engaged in 'deviant' behaviour (if not homosexual sex then illicit drug use). The study report states that, '[e]ven if deviance is not a central part of people's expressed attitudes to people with HIV, there is a level at which it underlies all discrimination, prejudice, and the excessive fear of HIV'.<sup>13</sup> The study found that HIV/AIDS-related discrimination could not be divorced from prejudice against risk groups such as gay men. People with HIV/AIDS were assumed to be members of risk groups and individual members of risk groups were automatically associated with HIV/AIDS regardless of their actual HIV status. That is, all gay men were seen as likely to be infectious. Furthermore, most people's reactions to HIV/AIDS were not determined by the fact that it was a presumed fatal disease, but by its association with gay men and drug users. The fear of being associated with these groups, and becoming the subject of such stigma oneself, was a large part of the fear of being infected with HIV.<sup>14</sup> The study's authors observed:

The more prejudiced members of the community believe that people living with AIDS and HIV should be placed under the control of the law and of the state, in order to prevent the spread of 'the plague'. Others endorse the view that there should be compulsory testing of persons from 'risk groups' to ensure control and the prevention of further spread...Punishment and retribution is enacted both at an institutional

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10 Editorial, 'AIDS Victims Receive Little Sympathy, Survey Shows', *Sydney Morning Herald*, 30 September 1991, p. 5.

11 NSW Anti-Discrimination Board 1992, *Discrimination—The Other Epidemic*, NSW Anti-Discrimination Board, Sydney.

12 Hollibaugh, Amber, Karp, Mitchell, Taylor, Katy and Crimp, Douglas (Interviewer) 1988, 'The Second Epidemic', in Douglas Crimp (ed.), *AIDS Cultural Analysis, Cultural Activism*, The MIT Press, Cambridge, Mass. For a detailed discussion on homophobic and AIDS-related discrimination in Britain, see Davenport-Hines, Richard 1990, *Sex, Death and Punishment*, Collins, London; also Watney, 1994.

13 Kippax, S., Tillett, G., Crawford, J. and Cregan, J. 1991, *Discrimination in the Context of AIDS*, Macquarie University Research Unit, National Centre for HIV Social Research, Sydney, p. 28.

14 Ibid.

level and an individual level in the refusal of treatment, gay bashing, incarceration, isolation, and avoidance of people suspected of being 'AIDS carriers'.<sup>15</sup>

Uncertainty about how far or how quickly HIV/AIDS would spread in Australia meant that in the 1980s fear of infection remained high even as the public became more educated about the physiology of HIV transmission. A second study, conducted in 1991 into public knowledge, attitudes and beliefs about AIDS, concluded that high levels of knowledge about HIV transmission did not reduce prejudice. The researchers concluded:

[The] community's knowledge about the nature of AIDS transmission, treatment and risk reduction is approaching saturation level, with 95 per cent or more correctly agreeing with propositions that have been central to community AIDS education efforts...Although knowledge levels about most issues may be satisfactory, our findings also point to a disturbing level of community hysteria about AIDS.<sup>16</sup>

According to the study's authors, the survey responses indicated a deep and often misguided concern about catching HIV/AIDS. More than half of the people interviewed believed that a policy of compulsory testing was warranted and a further 5 per cent believed all homosexuals should be tested.<sup>17</sup>

It is difficult to judge with any certainty how deeply or widespread public fears about AIDS were held, or the extent to which this had an impact on actual cases of discrimination against gay men and lesbians. It is, however, certainly clear why gay men were fearful of discrimination and/or legal sanction as a result of AIDS. The public was concerned about contracting AIDS and fears were exacerbated and shaped by the association between AIDS and an identifiable group of people who were already marginalised and stigmatised. Former President of the NSW Anti-Discrimination Board Steven Mark describes AIDS as having afforded homophobic discrimination 'a new heightened respectability in the community', representing 'discrimination on a new level'.<sup>18</sup>

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15 Ibid., p. 24.

16 Bray, Fiona and Chapman, Simon 1991, 'Community Knowledge, Attitudes and Media Recall About AIDS, Sydney 1988 and 1989', *Australian Journal of Public Health*, 15(2), pp. 107-13, at p. 112.

17 Ibid.

18 Steven Mark, TRC 2815/52, NLA.

The immediate response from the gay community and the fact that there was a gut response, but it was a united one, was critical. The fact that we had enough of an organised gay community to have a gay press, a gay bookshop, gay venues—we even had the argument about gay community versus gay movement. That was all going on. There was enough of that stuff and enough political self-awareness so that when this was on top of us we actually had a framework to respond with. It wasn't like we were just some little atoms of people, there actually was a centre—geographical and political—a heart where we knew the gay community was. And we knew each other very well. I don't know if we trusted each other very well, but I think we knew each other well enough to have a good working relationship. And that was enough to get started.

— Phil Carswell (2005a)

Discrimination was rife. So gay men were fighting on a number of fronts—for the right to have sex, for the right to work and live in the community as other people are able to do, for the right to anti-discrimination protection—a whole lot of things like that. So these were all motivators and there was a sense that a community was being built and here was something that threatened to decimate the community entirely. So they were part of motivating the gay community in Australia.

— Bill Whittaker (2004)

It wasn't really a particular person I knew who became positive, it was actually a general thing that, sometime late in '83 or early '84, the possible ramifications started to really come home to me—or what I thought the possible ramifications could be. And I was envisioning them as being quite drastic, because it seemed to me that it heralded the potential destruction of the community altogether. I always remember thinking quite clearly that what it could do would be to destroy most of the community institutions that we had. So that while we only had a sort of a relatively—or compared to now—a relatively small gay press, it seemed to me that that was very likely to go, that quite a number of gay businesses would collapse either because their proprietors would die or a lot of their customer base might die, so therefore the advertising base for the press would go as well.

— Don Baxter (1993)

## **Homophobia, Discrimination and Fear: The beginning of AIDS activism**

It was this environment of uncertainty and fear—occurring within the context of the history of homosexual discrimination—that shaped AIDS activism in Australia. First, gay communities were confronting an illness that, as far as anyone was aware at the time, inflicted a possible death sentence on anyone infected. No-one knew how quickly or how far the epidemic would spread, and the only thing that seemed clear was a link between gay men and this new disease. As activist Ken Davis recalls:

[Initially] I found it quite hard to believe that there was a viral agent causing cancer, because the initial attention was to the pneumonia and Karposi's sarcoma. That was hard to get your head around. But we knew that gay men were dying, we didn't know that anyone else was dying. So you've got to remember what it was like before we had a viral agent that we were sure of. We were assuming that gay men would randomly die and the only lead-up to it was being gay. That was pretty weird. That did feel like an act of God. We were fearful because we didn't know what we were dealing with.<sup>19</sup>

Alongside this uncertainty, people were realising the devastating impact AIDS could have on the lives of all gay people, even those not infected. In the early 1980s, homosexuality had been illegal in Australia for many more years than it had been legal. In fact, in many States it was still on the criminal code. There was certainly a feeling among gay men that law reform was tenuous and that AIDS had the potential to inspire not only re-criminalisation of homosexuality, but also increased restrictions on the freedoms of gay men and, by association, lesbians. Moreover, there were fears that individual acts of discrimination—gay bashing, workplace harassment, withdrawal of services and so forth—would become more frequent and more socially acceptable under the premise of avoiding AIDS.

## **Blood Politics: Beginnings of the AIDS movement**

AIDS screamed into mainstream public consciousness 1984 when it became known that people could acquire the virus through blood transfusions or donated blood products.<sup>20</sup> The media aired fears that the blood supply in

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<sup>19</sup> Ken Davis, Interview with the author, 5 November 2004. This particular quotation was in response to my question about what, in Davis's view, mobilised the gay community around AIDS.

<sup>20</sup> This occurred before the antigen for HIV was identified—although at the time there was a general medical consensus that AIDS must be a blood-borne virus due to the number of people who appeared to have

Australia could already be infected, sparking a realisation among the general public that AIDS could, and likely would, spread beyond populations of gay men and 'junkies'. Heterosexual adults and children were also vulnerable.

I think as young gay men we often didn't understand... We came to [activism] with an arrogance, that we couldn't believe we didn't have rights for a whole lot of things—other disease or disability groups were putting up with a whole lot of suffering that young gay men didn't think they had to put up with—particularly young, rich gay men, suddenly impoverished. But we demanded...often we demanded... entitlements with no conscience that other people didn't have those things. And a lot of the agitation around pensions and housing support and so forth worked because gay men didn't realise that that was the deal—this is what another impoverished or ill person is putting up with. We demanded all this special treatment. The end result was that it improved services for a lot of people. And it allowed other people to follow a bit of a path of taking on the medical providers or the social providers, and saying the nature of the relationship with the customer is different. And that's a good product of the activism. But we didn't strategise that, we just did that because we didn't know any better.

— Ken Davis (2004)

The first newspaper report on the possibility that the Australian blood supply could be infected appeared in *The Australian* on 2 May 1983, with an article discussing concerns of the British Health Authority that blood being imported from the United States might contain AIDS. As Australia did not rely on imported blood products, this article did not receive much reaction.<sup>21</sup> A short while later, however, Dr Gordon Archer, Director of the Sydney Blood Transfusion Service (BTS), put out a public call for 'promiscuous' homosexual men to voluntarily stop donating blood, declaring in a television interview that it was a 'virtual certainty' that the blood supply in Australia was already infected with AIDS.<sup>22</sup> Archer's call made front-page news across the country.<sup>23</sup>

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acquired AIDS through intravenous drug use.

21 Cook, Sue 1983, 'Disease Fear Leads Red Cross to Ban Gays as Donors', *The Australian*, 10 May, pp. 1–2; Ballard, John 1989, 'The Politics of AIDS', in Heather Gardner (ed.), *The Politics of Health: The Australian Experience*, Churchill Livingstone, Melbourne; Sendziuk, Paul 2001, 'Bad Blood: The Contamination of Australia's Blood Supply and the Emergence of Gay Activism in the Age of AIDS', in Elizabeth Ruinard and Elspeth Tilley (eds), *Fresh Cuts: New Talents 2001*, API Network and University of Queensland Press, Sydney.

22 Archer's call came before there were any identified cases of blood-product transmission in Australia although such transmission was known to have occurred in the United States and there was a realistic probability that Australia would face a similar problem (Sendziuk, 2001, p. 78).

23 Some within the BTS did not support Archer in his assertions. For example, the chair of the National Blood Transfusion Service (NBTS), David Penington, publicly responded that there was no risk of Australia's blood supply being infected with HIV because blood donation in Australia had always been entirely voluntary (apart from a short-lived experiment with a professional donor panel in 1938). Ballard, John 1999, 'HIV Contaminated Blood and Australian Policy', in Eric Feldman and Ronald Bayer (eds), *AIDS, Blood and the*

Archer made his call at a time when there was no test available to screen blood for HIV; indeed, HIV had not yet been identified as a virus. The only step authorities could take to prevent infection was to stop people who might be at higher risk of having AIDS from donating. Despite this, many members of the Sydney gay community were angered by Archer's announcement—not because they opposed having a policy on restricting blood donation, but because they felt those most affected by such a policy should be consulted about its terms and potential impact.<sup>24</sup> In 1983, homosexuality was still on the criminal code in New South Wales. The actions of the BTS seemed to offer further political fuel to those who opposed civil rights for gay men and lesbians. A member of a community organisation called the Gay Solidarity Group contacted Archer to request a meeting to discuss BTS policies. One option they wanted to investigate was whether Archer would be amenable to investigating the feasibility of introducing 'surrogate screening' for hepatitis B, rather than maintaining a policy that singled out particular groups. The Blood Bank had, for some time, been testing all blood donations for the hepatitis B virus—the antigen for which had been identified in the late 1960s. Ironically, this meant that in the 1980s there were large numbers of gay men who regularly donated blood, as they had been encouraged to do so as a means of being tested, anonymously and without cost, for hepatitis B and syphilis. The logic of surrogate testing was that if a person had been exposed to hepatitis B, there was a reasonable chance they had also been exposed to AIDS.<sup>25</sup>

According to activist Ken Davis:

[The] trouble with the blood ban stuff was that we said as soon as you say that you can't donate if you are a 'promiscuous homosexual', you're really missing the point of how to screen blood and that no one thinks of themselves as a promiscuous homosexual...If you want to formulate something that will exclude, let's talk about it. And the truth is that after that exclusion of promiscuous homosexuals, infection rates went up. And I don't think that was deliberate at all. I think people genuinely didn't understand and wanted to make a contribution and that gay men had been specifically targeted for blood donation for a decade before. So it was a real mess.<sup>26</sup>

Archer refused to meet with the Gay Solidarity Group. In response to this, participants at a Gay Rights Lobby (GRL) meeting organised a picket of the

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*Politics of Medical Disaster*, Oxford University Press, New York, p. 245. Penington was obviously making the assumption that the type of people who would be inclined to sell their blood for cash would be drug users or other people at greater risk of HIV.

<sup>24</sup> Don Baxter, Interview with James Waites, 26 November 1993, Oral History Project: The Australian Response to AIDS, TRC 2815/75, NLA.

<sup>25</sup> Ballard, 1999.

<sup>26</sup> Ken Davis, Interview with the author, 5 November 2004.

offices of the Sydney Blood Bank.<sup>27</sup> The picket was held on 13 May 1983. Placards and leaflets demanding 'Ban the Bigots, Not the Blood' were handed out, stating that the ban on gay donors could be counterproductive as 'closeted' gay men might feel the need to donate blood to prove their heterosexuality, particularly in a situation where they were donating with work colleagues, as was a common practice.<sup>28</sup> Unfortunately for activists, the picket turned out to be largely counterproductive as gay men were portrayed as putting their own interests above public health.

David Lowe says:

From a public relations point of view for the gay community, [the picket] didn't seem to me to be a sensible course of action. I suspect quite a lot of people must have shared those views and the picket didn't attract that many people, really. There were some people who had been politically active. But it certainly didn't seem to attract a broad consensus...I think it was a little bit unfortunate in a sense also because then it gave the people who wanted to call themselves 'innocent victims' the opportunity to blame the community: 'They have these pickets and want to donate blood'...It probably fuelled fears that some people were deliberately donating blood, which I don't think was the case.<sup>29</sup>

While not necessarily a successful event in its own right, the picket did lead to a number of other actions that proved more constructive. A number of individuals and groups met on 15 May 1983 to discuss the next steps in the 'AIDS campaign'. These groups included the Gay Rights Lobby, the Gay Counselling Service, the Gay Solidarity Group, the Metropolitan Community Church<sup>30</sup> and the Gay Business Association. From this meeting, the NSW AIDS Action Committee (AAC) was established.<sup>31</sup> The first success of the Sydney AAC was convincing the NSW Minister for Health to establish a ministerial advisory committee: the AIDS Consultative Committee. Membership of this committee included NSW Department of Health staff, medical specialists and representatives of the Sydney AAC.<sup>32</sup>

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27 The Melbourne Blood Bank did agree to a meeting with gay community activists. There were no similar protests to those that took place in Sydney. Phil Carswell, Personal communication, 25 October 2006, Melbourne.

28 Sendziuk, Paul 2003, *Learning to Trust: Australian Responses to AIDS*, UNSW Press, Sydney.

29 David Lowe, Interview with the author, 12 July 2005.

30 Metropolitan Community Church (MCC) Sydney is a Christian church that operates specifically to reach people excluded by established religious groups on the basis of sexuality. The MCC was an active part of the gay and lesbian community in the 1980s (and still is today) and participated in AIDS-movement initiatives.

31 Don Baxter, TRC 2815/75, NLA; Sendziuk, 2003.

32 Sendziuk, 2003.

As Ken Davis recalls: 'that was the genesis of AIDS activism, that small (inappropriate) picket of the blood bank that I wasn't at...that precipitated the State Government having to have a meeting between government, medical people and gay men.'<sup>33</sup>

## Prejudice and Queensland Babies

A few weeks after the Sydney Blood Bank picket, the National Blood Transfusion Service (NBTS) released a statement urging sexually active homosexual men, intravenous drug users and sexual partners of these people to abstain from donating. The NBTS had been careful to avoid a community reaction similar to that in Sydney by expanding the groups being asked not to donate beyond homosexual men and using the term 'sexually active' rather than 'promiscuous'. The blood transfusion services in other States also began to ask donors to sign declarations stating that they did not belong to the risk groups identified by the NBTS.<sup>34</sup>

The actions of the NBTS did little, however, to resolve the tension around HIV and blood donation, and the issue dominated headlines again in July 1984 when the first Australian case of AIDS known to have been acquired through a blood transfusion was diagnosed. In this case the blood donor, who was tracked by the Blood Transfusion Service, was a gay man who acknowledged that he was aware of the call for 'promiscuous' gay men not to donate but had not considered himself to be promiscuous. A short while later, the media reported that the same donor's blood had also been used in the preparation of Factor 8<sup>35</sup> and a number of people with haemophilia were being tested for AIDS.<sup>36</sup>

It was a few months after this, in November 1984, when the Queensland Government announced that three babies had died after receiving AIDS-infected blood, and that a donor known to be homosexual was to blame.<sup>37</sup> Probably not coincidentally, the announcement came in the middle of a federal election campaign and it quickly became a highly politicised issue. Public figures and

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33 Ken Davis, Interview with the author, 4 November 2004.

34 Ballard, 1999.

35 In Australia, 172 cases of HIV acquired through blood transfusions had been identified by the end of 1995 and some 264 people had been infected through blood products used to treat haemophilia (Ballard, 1999, p. 256). This represents approximately 30 per cent of Australians with haemophilia who treated their condition with blood products between 1980 and 1984. People with haemophilia were, in the 1980s, at particularly high risk of HIV infection as Factor 8—the product used to treat haemophilia—was made using the blood of a large number of donors. Hence, people using Factor 8 came into contact with the blood of many more donors than those who had a blood transfusion or received organ donations (Sendziuk, 2001, p. 82).

36 Sendziuk, 2001.

37 Langley, George and Rice, Margaret 1984, 'Three Babies Die of Suspected AIDS: QLD Acts Against Donors', *The Australian*, 16 November, p. 1.

political leaders started to weigh in on the debate about how to deal with AIDS, much of which focused on determining appropriate means by which to control or punish the actions of homosexual men who donated blood. In his speech at the opening of the National Party's federal election campaign, the then leader, Ian Sinclair, publicly declared that '[i]f it wasn't for the promotion of homosexuality as a norm by Labor, I am quite confident that the deaths of these three poor babies would not have occurred'.<sup>38</sup> The ultra-conservative Queensland Premier at the time, Sir Joh Bjelke-Petersen, also blamed the Federal Labor Government's stance on homosexuality, commenting that '[t]he Labor party is as much to blame with their acceptance of that type of low and disgusting lifestyle. And Mr Hawke is to blame by promising equal government support for homosexual marriages.'<sup>39</sup> 'Sir Joh' was backed by his Health Minister, Brian Austin, who, in discussing what punishment should be delivered to members of known 'AIDS risk groups' who donated blood, stated: 'You can't legislate to stop murder. You can put up signs telling people it's illegal to murder someone but that won't stop it.'<sup>40</sup>

The Blood Transfusion Service attempted to allay the blame being placed on the individual whose blood donation had infected the 'Queensland babies' by describing the donor as 'a person with a civic conscience' who had not realised they were an 'AIDS carrier'. A BTS official was reported as saying: 'He [the donor] had been very upset by the revelation and was now suffering extreme regret.'<sup>41</sup> Nevertheless, the Queensland Government, fuelled by sensationalist media, vitriolically continued to pursue punishment for the donor and introduce a punitive approach to protecting the blood supply.

Twenty-four hours after the babies' deaths had been reported, the Queensland Government passed legislation imposing criminal sanctions for false declarations by blood donors. If someone were to lie about their history of homosexuality or drug use when donating blood, they could now be held criminally liable.<sup>42</sup> Despite the reluctance of other State health ministers to impose legal regulations on blood donation, they agreed that all States needed to offer the same blood protection as Queensland. The legislation was adopted by other States a month later at the State Health Ministers' Conference. Australia was the only country in the world to have introduced such laws.<sup>43</sup>

There are two ways to look at this legislation. The first is that it was a pragmatic response to the need to protect the blood supply in the absence of any other

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38 Davis, Ian and Birnbauer, Bill 1984, 'Sinclair Links Labor with Deaths of Three Babies', *The Age*, 17 November, p. 1; Ballard, 1999.

39 'QLD Considers Manslaughter Charges: Sir Joh Cites ALP on AIDS', *The Canberra Times*, 4 December 1984, p. 1.

40 Ibid.; 'Now Labor Party Blamed for AIDS', *Northern Territory Times*, 4 December 1984, p. 1.

41 Langley and Rice, 1984.

42 Ibid.

43 Ballard, 1999.

means to screen for AIDS. But, while this was certainly the case, the legislation also suggests that authorities felt that the identified risk groups (gay men and intravenous drug users) needed to be controlled. The legislation was introduced amid a politically charged public debate within which prejudice towards gay men was overt. In effect, the moral discourse around homosexuality was translated into legal terms.<sup>44</sup> Furthermore, homosexual discrimination no doubt made it more politically risky for the State ministers to *not* introduce punitive action than it was to introduce it, and certainly State governments—particularly in Queensland—wanted to be seen to be taking decisive action around AIDS.

The media played a major role in directing public debate on this legislation, with commentaries in most major press outlets revealing a mistrust of gay men and their capacity to act responsibly in the face of AIDS. Adding fuel to this fire, newspaper headlines also ran with wholly unsubstantiated allegations that gay people were deliberately and maliciously infecting the blood supply, such as: 'Gays Accused of Giving Blood out of Spite.'<sup>45</sup> Editorials also engaged in this speculation. The broadsheet *The Australian*, for instance, ran a piece on 17 November 1984 that stated:

The chief medical officer of the NSW Health Department, Dr Tony Adams, believes that there may be a minority of homosexuals who are donating blood to rebel against society. It is hard to accept that anyone could be so vindictive as to take such action but when added to the revelation by a Sydney gay activist that some homosexuals who have recently given blood are now refusing to identify it for fear of persecution, it can only add fuel to the fire.<sup>46</sup>

An editorial in Brisbane's *The Courier-Mail* on the same date suggested that gay men were being irresponsible or selfish in their appeal for civil rights in the face of what could amount to a life or death situation for many people:

Clearly the medical authorities, both here and in other states, are doing everything possible to limit the spread of AIDS...Sadly, however, the actions of some members of the homosexual community have lacked responsibility and concern...Blood banks have appealed to male homosexuals not to give blood. Yet it seems for a number of reasons, these appeals have been ignored...It was not so long ago in our history that patients suffering other socially-unacceptable, contagious diseases, such as tuberculosis and leprosy, were locked away for what was considered the community good. No one is suggesting that this should happen to

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44 Hall, Ananda 1998, *A Risky Business: Criminalising the Transmission of HIV*, Faculty of Law Thesis, The Australian National University, Canberra, <[http://law.anu.edu/criminet/ananda's\\_thesis.html](http://law.anu.edu/criminet/ananda's_thesis.html)>

45 *Daily Telegraph*, 17 November 1984, quoted in Ballard, 1999.

46 Editorial, 'The New Plague', *The Australian*, 17 November 1984, p. 24.

homosexuals, but the aggressive activists in the movement should not be surprised if there is a violent community reaction to their cause as a result of this serious public health problem.<sup>47</sup>

Common to much of the media commentary at the time was the assertion that calls to punish gay men who donated blood were not based on homophobia, but were the sensible actions of public health authorities. People's moral opinions about gay men were ever present, but consistently denied. This was evident in a piece published by *The Australian* by high-profile conservative commentator Bob Santamaria, in which he claimed that the intention of his column was 'not to pass moral judgment on homosexual acts'. Rather, he writes: 'The sole question with which this column is concerned...is that of public health.' The piece goes on to argue that by claiming the right to privacy and confidentiality in order to ensure protection from discrimination, gay men were asking for extraordinary privileges. He writes that '[w]here public health is concerned, the infringement of the privacy of individuals is rightly held to be secondary to the threatened ravages of epidemic disease'. Gay men, he argues, should not have the right to demand civil freedoms if this contravenes public health priorities.<sup>48</sup>

While it is likely commentators such as Santamaria were genuine in their claims that they did not wish to pass moral judgment on gay men, they were asserting that gay men did not have a right to question or complain about the introduction of restrictions on their freedoms, rights or privacy. Activists who raised concerns about these infringements were heavily criticised for being selfish and irresponsible. The implicit suggestion in this was that if gay men were more 'responsible' there would be no need for such restriction of liberties. But gay men were not trusted with such responsibility and to some extent it seemed that the belief that gay men were to blame for AIDS drove much opinion on public health legislation.

On 8 December 1985, the front-page headline 'Die You Deviate' appeared in Melbourne's *Midweek Truth*. The father of one of the 'Queensland babies' who had died following a blood transfusion had made a public call for the donor—a gay man in his early twenties—to commit suicide or face capital punishment. The article reported the baby's father as saying: 'As the parents of this baby, we feel that the only honorable thing for the murderer of our son to do is to commit suicide.'<sup>49</sup>

Articles such as this depicted AIDS as a murder weapon rather than an illness, suggesting that gay men, not an indiscriminate virus, should be seen as the

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47 Editorial, 'AIDS and Responsibilities', *The Courier-Mail*, 17 November 1984, p. 4.

48 Santamaria, B. A. 1984, 'AIDS: Public Reaction and the Gay Community', *The Australian*, 27 November, p. 11.

49 'Die, You Deviate', *Midweek Truth*, 8 December 1985, p. 1.

'killers' of these babies. Even where there was no overt homophobic rhetoric, never was it suggested that those gay men who had been infected with AIDS also deserved sympathy or that they themselves were 'victims' of the disease. The standard practice was to present gay men as inflicting the illness on others, through intention or carelessness. In this way, beliefs about homosexual immorality and deviance played into the construction of AIDS in the public's imagination. HIV prevention was used to justify the curtailment of rights for gay men and lesbians, obscuring the moral opinion embedded in these calls. Activists who demanded a right to privacy and protection from discrimination were portrayed as acting against public health interests.

I was [a member of] the ALSO [Alternative Lifestyles Organisation] Foundation. I was on there as sort of the token leftie... So when they heard news in 1982 of this new thing happening in America, we got a health subcommittee together of four people: myself, the late Ian Dunstan, the late Chris Carter and the late Peter Knight. The four of us sat down together and said what are we going to do about this? Let's call a public meeting. What we decided to do, without any advertising, we booked the Dental Hospital in Melbourne, which was a bold move—we were a gay organisation booking a straight venue. We got a panel of doctors on stage, most of them gay, one straight, and through word-of-mouth filled the auditorium—700 people. Up to that stage, it was the largest political crowd of gay people I had ever seen in my life. I mean we had warehouse parties where we had 1000 people dancing and stuff, but it was the first time I had seen 700 people sitting down paying attention and being well behaved... It was really interesting how that word got through the party scene before it got through the gay press and through the gay political scene. The Drag Queens and the Leather Queens and the Qantas Queens all knew about it, and they knew something was going on that was going to be bad and they were all there in the audience, along with your established left-wing gay acts. That was the irony of the night. It was an amazing cross-section of people who had come there all through word-of-mouth. The networks already were established. That strength of community that was there was nascent—or latent. But it was still quite readily and easily tapped, and once it was tapped it was like a sleeping tiger. It wasn't going to sit down. At that meeting, I'll never forget it was two hours of absolute terror for me because every question we asked the doctors, they said: 'No, we don't know.' They said: 'This is what we do know, we've seen guys coming in and they're gone like that. They're dying within six months.'

This was before we knew about HIV or AIDS. It was just like they're getting sick, body covered in splotches, they were coughing, they were losing weight, they had night sweats, diarrhoea, they had enormous fatigue...So that meeting with 700 people, I'll never forget it, a lesbian activist by the name of Alison Thorne,<sup>7</sup> who is well known in gay history and so she should be—there was really a feeling of hopelessness through the whole room, people were thinking: 'Oh my god, what's going to happen to us, we're all going to die'—and Alison grabbed the microphone and did the classic Lenin thing, 'what is to be done?'. She said: 'Look at us. We've got to do something about this. I vote we have another meeting in one month's time at another venue and people can volunteer to take on various organising roles', or words to that effect. It was a stirring sort of 'man the battlements' (oh no, she'd never say that, it was 'staff the battlements'!) speech. It was amazing, it was the perfect line at the right time and it instantly galvanised the room. People said yes we can do this, we've got talented people here—we've got doctors, we've got lawyers, we've got policy people. So a month later we had a meeting at the Laird Hotel in Melbourne, a little pub in Collingwood. Ron, the owner, bless his heart (there are so many unsung heroes in this epidemic), gave us a room for free that night. So we crammed in about 35 to 40 people, which is more than we expected. We thought after a month it would die down and people would go back to their little holes. But in that room was the most amazing cross-section of people. It was like the big meeting shrunk down. You had your drag queens, your leather-boys, your political activists, then the sort of ALSO people and people who didn't do political things before but thought this was something they could possibly help with—like nurses and that sort of stuff. And because a lot of them were party people I knew most of them, so when they asked me to chair the meeting I got shoved into the fortuitous position of being the first chair of the first meeting of the Organising Committee on AIDS in Victoria. And I think Sydney had a similar meeting about a month earlier—we were very close. We'd been to Mardi Gras and things together, plus I had political allies in Sydney...So there was already stuff happening up there, so it was logical that we should do the same.

— Phil Carswell (2005a)

\* While in this text I make only passing reference to the role of lesbians, there were a number of lesbian women actively involved in the AIDS movement and in the subsequent establishment of AIDS organisations. The role that lesbians and heterosexual women played in AIDS activism could be the topic of an interesting thesis in itself. While this was not a topic that could be addressed with any depth in this text due to time and resource constraints, it is worth noting the role of lesbians as it shows that people within the gay community were motivated to take action around AIDS even if they did not feel personally at risk from the virus (lesbians were never identified as a 'risk group' for AIDS, even if they did become implicated to some extent in AIDS hysteria).

## Community and Organisation: The movement develops

By the time the ‘Queensland babies’ crisis erupted, the AIDS movement was well organised, operating through several State-based collectives: the Victorian AIDS Action Committee (VAAC), the NSW AIDS Action Committee (NSW AAC) and similar activists groups in other States.<sup>50</sup>

The first meeting of the VAAC had taken place at the Laird Hotel in Collingwood in July 1983.<sup>51</sup> Following this, on 4 December 1984, the VAAC held its first major public forum since this inaugural meeting. About 600 people attended. At this meeting, a decision was made to transform VAAC into what is now known as the Victorian AIDS Council (VAC). The VAC operated under a more formalised, incorporated structure—the change enabling the organisation to receive government grants (the Victorian State Government was unwilling and unable to fund an informal volunteer organisation).<sup>52</sup> Funding from the Victorian State Government was made available to VAC from 1985 through a grant from the State and Federal Governments’ joint-funding initiative.<sup>53</sup>

Phil Carswell recalls:

A telegram arrives for me as VAC President announcing a \$50,000 Commonwealth grant. We all cheer and wet our pants at the same time.

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50 This analysis focuses predominantly on Sydney and Melbourne as ACON and the VAC were the largest AIDS organisations and both provide a clear example of the strategies undertaken by the AIDS movement. There were, however, organisations similar to VAC and ACON that received government funding in Perth, Adelaide and Canberra. The Queensland story is a little different as this State was subject to the reign of ultra-conservative Premier Joh Bjelke-Petersen throughout much of the 1980s. The Queensland Government for many years actively campaigned against the involvement of the gay community in the AIDS response. Homosexuality remained on the criminal code in that State until 1990. Nonetheless, there was a community response to AIDS in Queensland. The Federal Government was able to override Bjelke-Petersen to some extent by funnelling money to the Queensland AIDS Council through a religious charity. Phil Carswell, Interview with the author, 23 July 2005.

51 Phil Carswell, Interview with the author, 23 July 2005. From this date, the VAAC began organising educational initiatives, producing ‘safe sex’ information and campaign materials. Volunteers were recruited for care, support and general assistance even before VAAC had any clients (the official AIDS case load in Australia at the end of 1983 was only seven, though this number increased significantly throughout the following year). The first fundraising efforts focused on improving patient facilities at Melbourne’s Fairfield Hospital, which was the main hospital for people with AIDS, starting with the rundown patient lounge at the end of the Ward Four corridor. Ibid.; Tobias, Sandy 1988, *AIDSLINE—A Profile*, Unpublished paper, Victorian AIDS Council, Melbourne; Altman, Dennis 1990, ‘Introduction’, in Richard Clayton (ed.), *Gay Now, Play Safe*, Victorian AIDS Council/Gay Men’s Community Health Centre, Melbourne.

52 Phil Carswell, Interview with the author, 23 July 2005; Phil Carswell, Excerpt from personal notes made for a presentation on the history of the AIDS epidemic at Sydney University, 2005c; Altman, 1990.

53 Funding was tied to specific projects, with clear anticipated outcomes and a limited time frame. VAC was able to secure funds for administration of the organisation in 1986. Morcos, Monica 1968, ‘Money Matters’, *Annual Report*, Victorian AIDS Council, Melbourne, p. 13. The same year, VAC negotiated with the State and Federal ministries of housing to secure a property in which to accommodate people living with AIDS. VAC would provide nursing, 24-hour care and support for residents. Carr, Adam 1987, ‘President’s Report’, *Annual Report*, Victorian AIDS Council, Melbourne.

This is the largest amount of money anyone of us had thought possible... This also saw the formation of the Gay Men's Health Resources Project, which later became the Gay Men's Health Centre [GMHC] and the recipient of most of the money... The original idea was to establish a user-friendly clinic and health service that could also focus on broader gay health issues such as alcoholism and drug use, STIs [sexually transmitted infections] and the impact of discrimination.<sup>54</sup>

A similar process occurred in Sydney with the NSW AAC being reformed into the AIDS Council of New South Wales (ACON) in February 1985.<sup>55</sup> ACON's foundation meeting was held at the Teachers' Federation Hall in Sussex Street in the city and was attended by more than 500 people.<sup>56</sup> ACON was an amalgamation of several organisations that had been set up in response to HIV/AIDS, including the AAC, the Bobby Goldsmith Foundation,<sup>57</sup> the Community Support Network (CSN)<sup>58</sup> and Ankali support service.<sup>59</sup> By 1989, ACON and the CSN had about 700 members in New South Wales. This included branches in

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54 Phil Carswell, Excerpt from personal notes made for a presentation on the history of the AIDS epidemic at Sydney University, 2002.

55 Sendziuk, 2003.

56 Don Baxter, TRC 2815/75, NLA.

57 Bobby Goldsmith was a gay man who died in June 1984 of medical complications caused by AIDS. Bobby was active in Sydney's gay scene and community activities (particularly sporting activities) and had a wide range of friends. When Bobby became ill, a group of his friends arranged care and support for him at his home so he was able to avoid hospital. When medical equipment was needed to assist his care, Bobby's friends raised funds for things such as a wheelchair, commode and special support mattress. When Bobby died, the Bobby Goldsmith Foundation Incorporated (BGF) was established in his name. BGF is a fund that supports people with AIDS-related illnesses to be cared for in their homes. Bobby Goldsmith Foundation 1999, *Who Was Bobby Goldsmith?*, Bobby Goldsmith Foundation web site, viewed 24 April 2004, <<http://www.bgf.org>>

58 Community Services Network Incorporated (CSN) is a volunteer-based community group that provides in-home care for people with AIDS-related illnesses. AIDS Council of NSW (ACON) 2006, *Community Support Network*, ACON web site, viewed 20 May 2006, <<http://www.acon.org.au>> CSN developed from the AIDS Support Group and AIDS Home Support, which were established by Terry Goulden, a founding member of the Gay Counselling Service. These support services ran alongside the AAC, but were kept separate from political activities as Goulden was concerned that the politics might alienate potential allies. When the AAC was reformed into ACON in February 1985, however, these care and support services were integrated with the other functions of ACON. As an example of the extent of volunteer labour coordinated by CSN, throughout the 1990–91 financial year, CSN staff and volunteers did 11 874 shifts for their 173 clients. This amounted to more than 72 000 hours. The majority of these hours were dedicated to direct care of clients in their homes. Malcom, Anne 1991, 'Community Services Report', *Annual Report*, AIDS Council of NSW, Sydney.

59 'Ankali' is an Aboriginal word meaning 'friend'. The Ankali project was established in 1985 in Sydney. The project trains volunteers to provide one-on-one support to people with AIDS as well as their partners, families and friends. Ankali is now linked to the Albion Street Centre, an HIV/AIDS service and medical clinic funded by the NSW Government. South-East Sydney Area Health Service (SESAHS) 2006, *Ankali*, SESAHS web site, viewed 21 November 2005, <<http://www.sesahs.nsw.gov.au/albionstcentre/Ankali/index.asp>> Don Baxter, Interview with James Waites, 26 November 1993, Oral History Project: The Australian Response to AIDS, TRC 2815/75, NLA; Ariss, Robert 1993, 'Performing Anger: Emotion in Strategic Responses to AIDS', *Australian Journal of Anthropology*, 4(1), pp. 18–30.

Sydney, Newcastle and on the North Coast. ACON's governing council included 12 elected committee members (unpaid) and the organisation had 25 full-time staff.<sup>60</sup>

In 1985, representatives from AIDS committees and councils from across the country, who had been attending the First National AIDS Conference, passed a vote to establish a national federation of AIDS organisations, to be named the Australian Federation of AIDS Organisations (AFAO).<sup>61</sup>

AFAO, VAC, ACON and other community-run HIV/AIDS organisations across the country, such as the AIDS Action Council of the Australian Capital Territory and the WA AIDS Council, formalised and centralised the base from which activists worked. As Graham Willett writes:

The work was transforming the activists as much as they were transforming the world. It is not an accident that a shift from 'action committee' to 'AIDS Council' took place in late 1984 and early 1985 as the government and gay activists started to work more closely together. The shift in nomenclature marked a shift in outlook by the organisations and those running them. Adam Carr, who first proposed the change, saw 'council' as evoking respectability and authority, a gathering of experts and their expertise, appealing more to governments, bureaucracies and medical professionals than action committees.<sup>62</sup>

In the early 1980s, the AIDS movement quickly and strategically established a dialogue with the Federal Government. For example, in September 1983, a meeting was organised between the Federal Health Minister, medical researchers and members of the NSW and Victorian AIDS Action Committees. At this meeting, the Health Minister, Neal Blewett, made it clear that the Federal Government was prepared to denote a formal role for the community sector in the AIDS response if they were willing and capable to undertake this.<sup>63</sup> With the relationship already established, activists were later given an opportunity to meet with Blewett and his advisor, Bill Bowtell, to advocate their position on the 'Queensland babies' scandal in 1984.<sup>64</sup>

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60 Don Baxter, TRC 2815/75, NLA; AIDS Council of NSW (ACON) 1989, *Future Directions for the AIDS Council of NSW: A Strategic Planning Document*, ACON, Sydney.

61 Carswell notes that the Queensland AIDS Committee (QuAC) had some initial reservations as their membership was broader than the gay community and they were concerned that AFAO was primarily gay oriented. Phil Carswell, Interview with the author, 23 July 2005.

62 Willett, Graham 2000, *Living Out Loud: A History of Gay and Lesbian Activism in Australia*, Allen & Unwin, Sydney.

63 Although, as Carswell notes, because the AACs were still in their infancy at the time and not highly organised, the community did not follow up on this meeting as effectively as they could have. Phil Carswell, Interview with the author, 23 July 2005.

64 Phil Carswell, Interviews with the author, 23 July and 17 December 2005.

On the back of this, in late 1984, representatives from the Victorian and NSW AIDS Action Committees, Phil Carswell and Lex Watson, were invited to join the new National Advisory Committee on AIDS (NACAIDS). The committee was set up to advise the Federal Government on human and social aspects of AIDS. It was chaired by prominent Australian media personality Ita Buttrose. Other appointees to NACAIDS included Jennifer Ross from the Haemophilia Foundation, Anne Kern from the Commonwealth Health Department, representatives from the NSW and Victorian Health Departments, the Australian Medical Association and the Royal Australian Nursing Federation.<sup>65</sup>

The appointment of Carswell and Watson to NACAIDS gave the AIDS movement a legitimate place in AIDS policy making. As Carswell points out, the fact that the AIDS movement had two people on the committee meant they were able to both move and second motions, giving them a reasonable amount of power around the committee table.<sup>66</sup> Although they certainly adapted to their new situation, the level of authority afforded to the AIDS movement through their role on NACAIDS was unanticipated by many activists. A number of people had previous experience in political lobbying, but to actually sit on a government advisory body and develop personal relationships with high-level decision makers, including a Federal Government minister, was a new experience.

According to Ian Rankin:

Over time, the community sector has become more confident that it is entitled to be funded. Certainly in the early-to-mid 1990s I still had a sense that people were surprised that we were allowed to sit around ministerial advisory tables or comment on research programs, etc. We'd come out and boldly claim it. But everyone would still be a bit surprised when it actually happened. I think during the course of the '90s people became more comfortable with the idea that the community sector was valid, should be represented, did have something to say and something to contribute.<sup>67</sup>

Building a working relationship with the Federal Government proved to be an extremely important tactic of the AIDS movement in terms of gaining access to funding and political power, and establishing the public profile of

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65 Now the Australian Nursing Federation. Altman, Dennis 1992, 'The Most Political of Diseases', in Eric Timewell, Victor Minichiello and David Plummer (eds), *AIDS in Australia*, Prentice Hall, Sydney; Phil Carswell, Interview with the author, 23 July 2005.

66 Phil Carswell, Interview with the author, 23 July 2005.

67 Ian Rankin, Interview with the author, 26 July 2004.

activists.<sup>68</sup> Despite the formalised status of the AIDS councils, there was no doubt, however, that it was the strong base of community support that gave them their political strength in the 1980s and early 1990s. The AIDS movement continued to attract a much broader constituency than those involved directly with the formal organisations. Large numbers of non-aligned activists took part in volunteer community work, and traditional protest strategies such as street demonstrations and lobbying continued to be a feature of AIDS-movement activity.

Bill Whittaker explains:

What happened is in Australia a number of people came forward, mainly gay men but a couple of exceptions—Margaret Duckett, for example, who just emerged and had skills in lobbying. But a number of gay men who had the skills because of what they had done in the past—lobbying, policy, people who knew how government worked came forward and had skills and were effective. But also there were groups of gay men who...didn't have any of those skills. They were not particularly sophisticated but were brave enough to speak out, turn up and that was very important.<sup>69</sup>

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68 Despite the political authority afforded by the AIDS movement's relationship with the Federal Government, questions began to be raised about the limitations imposed on the movement once they were operating with government funds and had activists sitting on official advisory boards. There were fears that the movement had become 'coopted' by government and therefore less able to advocate independently the interests of the gay community. Although I do not discuss these issues further in this text, they are important considerations in terms of studying movement building in the longer term. In Australia, concerns that government funding had the potential to demobilise collective action were, to some degree, justified when the Liberal Party won the federal election in 1996, under the leadership of John Howard. The Howard regime began a program of cutting funds to non-governmental organisations. Organisations that publicly criticised the Government, or were actively campaigning against government initiatives, began to feel that their funding was under threat. Many argue that the political efficacy of non-governmental agencies was significantly hampered in this political climate in a way that it was not under the Labor Governments of the 1980s and early 1990s. As AIDS organisations were still partially funded by the Federal Government, some argued that the capacity of the AIDS movement was undermined by the reliance of these organisations on government funds. Even if activists not affiliated with a formal AIDS organisation were to take action against the Government around AIDS, it arguably could threaten the funds of organisations such as ACON and VAC. Staples, Joan 2006, *NGOs Out in the Cold: The Howard Government Policy Toward NGOs in Democratic Audit of Australia*, Discussion Paper 19/06, Faculty of Law, University of New South Wales, Sydney, viewed 3 June 2006, <[http://democratic.audit.anu.edu.au/papers/20060615\\_staples\\_ngos.pdf](http://democratic.audit.anu.edu.au/papers/20060615_staples_ngos.pdf)>, p. 2; Tabone, Joey 2004, *Australia's Response to HIV/AIDS at Risk Through Lack of Leadership from the Commonwealth Government*, Media release, 18 May, AIDS Action Council of the ACT, Canberra, viewed 20 November 2005, <<http://www.AIDSaction.org.au/content/media/2004/responsetohivAIDS.php>> That said, most people interviewed for this text who were involved with ACON and VAC in the early 1980s acknowledged that the partnership with the Labor Federal Government in the 1980s was politically advantageous and progressive—even radical—for its time. Ken Davis, Interview with the author, 4 November 2004.

69 Bill Whittaker, Interview with the author, 6 November 2004.

If you're talking about what caused people to act from a compassionate side of it then I think two things happened. One was again, within an organised gay community, people acted philanthropically and compassionately because they were being actively discriminated against by the broader community. So, for example, it should never have been the case that there was a need to develop an organisation such as CSN [Community Support Network].\* It was the case, it was definitely the case, that people were dying in their homes because home care wouldn't come and look after them. [People were] scared of catching [HIV] and that being manifest, even if they didn't say they were scared, into hostility toward people with HIV. Yeah, a downright, flat-out refusal to go and care for people! I'm talking about a time in the early '80s where you had people in hospital in Prince Henry where nursing staff were having to feed patients, if there were nursing staff that were prepared to be working there (nursing staff numbers were quite small). Loved-ones had to come in and feed their patients because the catering staff refused to do anything but leave trays at the front steps of the ward. Now in an environment like that you have to act. It is wrong that you have to act, it is wrong that you have to establish a parallel process. But there is a period of time in which you do have to do that. When I say people were acting benevolently...if you think in the very early '80s with the first fundraising activity that was put on by a group of gay men in Sydney which was to raise money for a guy called Bobby Goldsmith so he could remain at home and die at home rather than have to be hospitalised. And we're talking about a situation where if there wasn't money made then his rent wouldn't be paid and he wouldn't have anywhere to live. So you put those sorts of things together...the reason BGF [Bobby Goldsmith Foundation] sprung up at the time was because that man could not stay at home without being assisted by groups of peers and friends and that group, BGF, worked very closely with CSN to provide them with the necessary goods they require to keep someone at home.

— Levinia Crooks (2005)

\* The Community Support Network (CSN) was one of the first home-care and support services set up for people with AIDS. It was established at a grassroots level by people within the gay community and was entirely volunteer run. CSN still exists today. Now it has some paid staff and is linked to the AIDS Council of NSW.

## AIDS and Gay Politics

The AIDS councils were very much integrated with the gay community. They had a broad support base and many community members were involved. The gay press also ensured that the community was consistently made aware of what the AIDS councils were doing. Moreover, HIV/AIDS was an issue that drew

the gay community into political action in a way that other issues never had. Literally hundreds more people were politically active around HIV/AIDS than had ever been around issues such as law reform, and there was a high level of awareness among gay men about the politics of HIV/AIDS, even those with no direct connection to AIDS activism. Indeed, throughout the 1980s gay politics became enmeshed with the politics of AIDS. Lex Watson, a founding member of ACON, once wrote:

[AIDS] has affected all gay men in a way in which law reform, nice idea though it was (and much though I spent years doing it), did not really do. Many gay people thought anti-discrimination was wonderful, many people felt more confident because of it, many people were very glad they had it. But it didn't, very often, directly and immediately change their lives. AIDS has. And AIDS has consequently rewritten the gay male script in a way that nothing else has. Perhaps one could argue that the Mardi Gras in Sydney, as a gay community event, has come the closest to this far-reaching impact, but AIDS has a very particular resonance.<sup>70</sup>

The AIDS councils became a major organising body for the gay community. Although the government funding they received was primarily directed towards HIV-prevention initiatives, the AACs and the AIDS councils did not lose focus on their objective of protecting the rights and freedoms of gay men and lesbians.<sup>71</sup> Their political intent in this respect was clear from the beginning.<sup>72</sup> For example, when the Sydney AAC was established, they announced their formation in a letter to Neal Blewett, stating that the AAC aimed to, among other things, 'monitor available information on AIDS and provide non-alarmist information to both the gay community and the wider media in order to counter the political attacks on homosexuals that had become adjunct to the AIDS debate'.<sup>73</sup> In Melbourne, a media report in *The Age*, titled 'Gays Form AIDS Group', stated:

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70 Bill Whittaker, Interview with the author, 6 November 2004.

71 This is not to say that the AIDS action councils, VAC or ACON were against working with other groups or did not see the importance of approaching HIV/AIDS more broadly than the gay community. Over time, the VAC and ACON began to work with other groups affected by HIV, including women, heterosexual men and Indigenous people. Historically, however, it was the gay community that developed these organisations and a large part of their *raison d'être* was the protection of gay rights.

72 Michael, Dean 1987, 'The Political Action Working Group', *Annual Report*, Victorian AIDS Council, Melbourne.

73 Cited in Sendziuk, 2003, p. 74. The AIDS action councils were also given a mandate from the gay community to speak on their behalf. Public meetings took votes allowing the councils to formally represent the gay community, which helped to sideline those who professed to be spokespeople without any community backing (such as Paul Dexter, who claimed to be head of an organisation called the 'Gay Army' although he was the only recruit). Carswell, Phil, Unpublished speaking notes for presentation at conference Retrospectives: HIV/AIDS in Australia, Historical Perspectives on an Epidemic, 27 May 2002, University of New South Wales, Unpublished notes and personal communication with Jennifer Power, 23 July 2005.

Melbourne's homosexuals yesterday announced the formation of a special group to combat what it regards as ignorance and hysteria about acquired immune deficiency syndrome, AIDS. A spokesperson for the Victorian AIDS Action Committee, Mr Adam Carr, said that the group has been set up to speak for the homosexuals in any working groups studying AIDS, to counter incorrect information being spread about the disease and to resist any attacks on homosexual people prompted by the disease. 'We reject any suggestions that AIDS is in any way a gay plague or other similar phrases used out of ignorance or malice,' Mr Carr said. 'We reject any suggestions that homosexuals or any other minority group are responsible for the outbreak of this disease. We will defend the gay community from these attacks.'<sup>74</sup>

The AIDS councils ensured that the media published information about their initiatives, and, amidst the articles that expressed concerns that gay men were spreading AIDS, more positive stories began to appear. For example, on 31 May 1983, the *Launceston Examiner* ran the headline 'Homosexuals to Fight Lethal AIDS'. The article stated that 'Sydney's homosexual community has called for a national seminar to find how best to combat the mysterious AIDS disease that has killed at least 600 people in the US'.<sup>75</sup> The *West Australian* newspaper in the same year reported on actions being taken by the Campaign Against Moral Persecution (CAMP) to inform gay men about AIDS. The article noted that medical specialists had commended a bulletin prepared for gay men by CAMP.<sup>76</sup> In 1985, the *Sydney Morning Herald* ran a headline that read 'Gays Want Govt Help to Prevent AIDS'. The story went on to explain why the AIDS movement was calling for government funding for community AIDS initiatives. It also mentioned that 60 000 brochures about AIDS were already being distributed by the AIDS councils.

The formation of AIDS councils, and the subsequent funding of these councils by the Federal and State Governments, meant two things for gay and lesbian rights. First, for the first time in Australia's history, groups advocating gay and lesbian rights received significant levels of government funding. Second, the political influence of these groups gave them the capacity to establish a strong media profile.

The fear of AIDS was as much a product of the social history and social position of gay men and lesbians as it was about the terror of this unknown, fatal disease. People reacted to the felt experience of injustice that had long been part of life for gay men and lesbians. But also, within the gay community, there was

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74 'Gays Form AIDS Group', *The Age*, 8 August 1983, p. 5.

75 Needham, Paul 1983, 'Homosexuals to Fight Lethal AIDS', *Launceston Examiner*, 31 May, p. 6.

76 'WAs Homosexuals Warned on AIDS', *West Australian*, 21 May 1983, p. 23.

a collective sense that people needed to protect themselves from the social/political ramifications of AIDS. In the beginning, this was not necessarily a clearly articulated political position so much as an undercurrent of knowledge about gay history that circulated within the community, compelling people to take action. As activist Ken Davis put it: 'My generation...I don't know what we thought we were going to achieve. But we didn't have a choice because we thought we were going to be locked up or dead.'<sup>77</sup>

But as the AIDS movement developed, so did a growing sense of political self-assurance among movement actors. This could be seen in the increasing expectation among activists that the gay community should be consulted by the media on matters concerning HIV/AIDS and that AIDS organisations could, and should, be given funding for their work. Activists gained confidence in their right to be publicly and politically recognised for their work in the AIDS sector and the AIDS movement grew stronger as a result.

[In] the gay community there was a capacity to behave in an organised, political way because if you consider the timing of when HIV came along, it came along at a time when the gay community (gay male community, although there was a lesbian community it wasn't ever as illegalised nor at the time as organised)... so the gay boys were fighting for political rights, they were out and about and outspoken, they were forming organisations. So we're talking about a group who were skilled, articulate and organised. And on that foundation came HIV...[In] Melbourne they had gone down the path of developing an organisation called ALSO [Alternative Lifestyles Organisation]. At the time that HIV came along ALSO had been raising funds in order to establish a gay and lesbian retirement village, or some sort of aged care facility. That money got diverted into the AIDS Council to put up a mechanism to respond to AIDS. In Sydney, the people who had been involved in the gay rights movement immediately became the people who were involved in HIV. So politically what drove people to action was the fact that they had a nascent community, and [an] incredible amount of political will and intellect drawn into that and they saw that they stood to lose everything if they didn't act. There was a potential there to lose any of the benefits.

— Levinia Crooks (2005)

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77 Ken Davis, Interview with the author, 4 November 2004.

## HIV and the Australian State

The role of the Australian state is an important part of the history of HIV/AIDS in Australia. While the focus of this text is community action, the role of the Australian Federal Government in the response to AIDS provides an important backdrop to this discussion that deserves some space here.

Health in Australia is traditionally the responsibility of State governments. When AIDS arrived, however, it was the Federal Government that took charge of developing and implementing policy. There were several reasons for this. First, the nature of the epidemic meant it was politically unsavoury and risky territory for politicians. They did not want to deal with issues relating to illegal drug use, prostitution or gay men. Cost was another concern. In the mid-1980s, there were estimates of an epidemic far more widespread than that which eventuated in Australia, and State health ministers were keen to ensure that the Federal Government took major financial responsibility for it.<sup>78</sup>

After a long period in opposition, the Australian Labor Party came to power under the leadership of Bob Hawke in 1983. When the Cabinet was appointed, former Rhodes Scholar Neal Blewett took up the position of Health Minister. Blewett recalls that in his first briefing as minister there was some mention of an illness that was affecting gay men, but the issue was not given high priority. At the time, the matter at the top of his agenda was the reintroduction of a universal health insurance system: Medicare. He also planned to institute changes to the Pharmaceutical Benefits Scheme and revive former Prime Minister Gough Whitlam's system of community health programs. AIDS, however, became a core priority of Blewett's period as Health Minister over the course of the 1980s.<sup>79</sup>

Blewett is broadly credited with being central to the 'successful' Australian response to AIDS. It was under his leadership that what came to be known as the community/government 'partnership' approach to AIDS was forged. This model involved provision of funds to non-governmental groups, such as the gay community-run AIDS councils, to enable them to organise prevention and education initiatives at a grassroots level. The model was also applied to other community groups, with funding, for example, being provided to the Australian Prostitutes' Collective and injecting drug user advocacy groups.<sup>80</sup>

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78 Blewett, Neal 2003, *AIDS in Australia: The Primitive Years, Reflections on Australia's Policy Response to the AIDS Epidemic*, Australian Health Policy Institute Commissioned Paper Series 7, University of Sydney, NSW, viewed 5 May 2006, <<http://www.ahpi.health.usyd.edu.au/pdfs/colloquia2003/AIDSpaper.pdf>>

79 Ibid.

80 This partnership model had actually first been established in Victoria, when the Victorian Government agreed to fund the development of the Gay Men's Community Health Centre run by the Victorian AIDS Council. Ballard, John 1998, '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*, Cambridge University Press, Melbourne.

Establishing a working relationship with affected communities was no doubt a feature of Blewett's personal political style. He was also, however, strongly influenced by his senior advisor, Bill Bowtell, who was personally involved with gay community activism. There were also some political precedents that supported Blewett's approach. In 1972, when the Labor Party had briefly been in power under the stewardship of Whitlam, they introduced a series of community health programs that aimed to improve the accessibility of health care. A NSW consortium called Consumer Health Involvement was established, with several subgroups that looked at issues of improving information to consumers and enhancing consumer involvement in policy decision making.<sup>81</sup> This program was scrapped when the Liberal Party took over government in 1975. In 1983, however, when Hawke was elected Prime Minister, there was an expectation—flowing from Whitlam's influence—that there would be a renewed emphasis on community involvement in health.<sup>82</sup> The Commonwealth Department for Health was also about to be thoroughly restructured under a new Secretary, Bernie McKay. The changes were to include greater emphasis on preventative health through a new Health Advancement Division.<sup>83</sup> Also in Australia, the Women's Health Movement had established some models for community involvement and leadership in health and provided an example of the process by which community advocates were able to gain influence within the government bureaucracy.<sup>84</sup> Despite the existence of these precedents to support Blewett's approach to HIV/AIDS, it was still a brave move for a government minister to publicly declare his faith in the capacity of stigmatised groups such as gay men and sex workers to take the lead in preventing a major epidemic.

As well as funding community groups, the Blewett ministry established a structure for consulting the community on AIDS. The National Advisory Committee on AIDS (NACAIDS) first began meeting in 1984, chaired by Ita Buttrose, and included two representatives from the gay community. Representation on NACAIDS was an important political opportunity for the AIDS movement. As one of the community representatives, Don Baxter, recalls:

The other thing [NACAIDS] did was give those of us who were on there the direct access, personal access to people who were making the decisions. So, while the meetings themselves might have been messy, we always had informal direct links—or even formal ones. I mean you could

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81 Altman, 1992.

82 Crichton, Anne 1990, *Slowly Taking Control? Australian Governments and Health Care Provision, 1788–1988*, Allen & Unwin, Sydney; Ariss, Robert 1997, *Against Death: The Practice of Living with AIDS*, Gordon and Breach, Amsterdam.

83 Ballard, 1989.

84 Ballard, John 1997, 'Australia: Participation and Innovation in a Federal System', in David Kirp and Ronald Bayer (eds), *AIDS in the Industrialised Democracies: Passions, Politics and Policies*, Rutgers University Press, New Brunswick, NJ; Ariss, 1997.

write to people quite easily and all of that. So, it actually facilitated community sector communications to chief decision makers in a way that never happened in the US or UK or lots of other places.<sup>85</sup>

The community model was politically risky for the Federal Government. At the time there was no precedent for such a model and it involved giving large sums of money to widely mistrusted and stigmatised groups. Many authors note, however, that the model provided political benefits as well. John Ballard, for instance, argues that the community-funding model adopted by the Australian Government could be considered an effective method of governing 'at a distance'.<sup>86</sup> It allowed the Government to claim credit for successes in HIV prevention, while distancing themselves from any materials or initiatives that attracted political or public protest, such as explicit posters produced by the AIDS councils in their HIV-prevention work. This fitted with the longstanding Australian tradition of the use of statutory authorities and royal commissions—autonomous from government—to undertake work that might create political threats.<sup>87</sup> Dennis Altman similarly notes that the willingness of the Federal Government to fund AIDS councils was a reflection both of 'political pressure and of a cynical recognition of the usefulness to governments of groups able to perform certain services either more cheaply...or at arm's length'.<sup>88</sup> Many people who were involved in the AIDS sector at the time also acknowledge, however, that it simply made sense for the Government to consult with the community. At that stage, the Government was desperate for information about AIDS and the gay community in Australia, whose media had been reporting on AIDS since 1981, held most of that knowledge.<sup>89</sup> Moreover, the partnership that developed between the community and the Federal Government in response to HIV/AIDS was unique, and a testament to the capacity of the gay community to organise their response. As community activist Lou McCallum writes: '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 response to AIDS'.<sup>90</sup>

It is not the intention of this text to divert the historical focus from the importance of the decisions made by Neal Blewett and his advisors in response to HIV/AIDS. Indeed, the impact of HIV/AIDS would likely have been significantly

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85 Don Baxter, TRC 2815/75, NLA.

86 Ballard, 1998.

87 Ballard, 1989.

88 Altman, 1992, p. 63.

89 David Plummer, Interview with the author, 30 August 2004; Bill Bowtell, Interview with the author, 28 May 2005; Bill Whittaker, Interview with the author, 6 November 2004.

90 McCallum, Lou 2003, *Review of Paper by Neal Blewett*, Australian Health Policy Institute Commissioned Paper Series 7, University of Sydney, NSW, viewed 5 May 2006, <<http://www.ahpi.health.usyd.edu.au/pdfs/colloquia2003/AIDSpaper.pdf>>, p. 33.

more devastating in Australia if the Government of the day had pursued a more conservative approach to disease prevention. Strategies implemented under Blewett's stewardship—including the involvement of affected communities and implementation of programs such as the needle/syringe exchange (where injecting drug users were given free access to clean syringes)—have proven in the longer term to be extremely effective HIV/AIDS prevention measures.<sup>91</sup> A supportive Federal Government also represented an important 'political opportunity' for the AIDS movement in that they were afforded a legitimate role in the policy response to HIV/AIDS and funding was provided for community-run education and prevention initiatives.

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91 See, for example: Blewett, 2003; Drummond, Michael, Health Outcomes International and the National Centre for HIV Epidemiology and Clinical Research 2002, *Return on Investment in Needle and Syringe Programs in Australia*, Department of Health and Ageing, Canberra; Feachem, Richard 1995, *Valuing the Past—Investing in the Future: Evaluation of the National HIV/AIDS Strategy 1993–94 to 1995–96*, Department of Human Services and Health, Canberra.