HIV/AIDS AND AUSTRALIA'S COMMUNITY-BASED SECTOR:

A SUCCESS STORY IN HIV PREVENTION

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1. INTRODUCTION

Australia has, in the words of former Commonwealth Minister for Community Services and Health, Dr Neal Blewett, "turned a very brave, bold and determined face to AIDS; we have found and shown a national maturity and strength".¹

This paper explores the role of community based organisations in that response, documenting the successes and addressing some problem areas.

2. BACKGROUND

Health education programs as a whole tend to follow one of two theoretical frameworks: a very traditional model of health education for disease prevention, where objectives emphasise individual risk assessment and behaviour; and a second public health framework most clearly articulated in the 1986 Ottawa Charter, to which Australia is a signatory.

This second approach refocusses action towards social and environmental change and emphasises changes through collective values and action as a major agent in individual behaviour change.

The Charter canvasses five areas for health promotion action:
1. Promoting health through public policy
2. Creating a supportive environment
3. Developing personal skills
4. Strengthening community action
5. Reorienting health services

This new public health approach has provided the basis for Australia’s national response to HIV/AIDS.²

3. THE NATURE AND IMPACT OF COMMUNITY SECTOR INVOLVEMENT IN HIV/AIDS

Community sector involvement in HIV/AIDS is much broader than is commonly supposed.

A diversity of communities have become involved in HIV/AIDS in Australia. These communities have organised on a formal basis to varying degrees and have received varying levels of recognition and funding from Government.


² Quite clearly, senior decision-makers in Australia had been influenced by the debates on effective public health approaches prior to the public drafting and release of the Ottawa Charter.
Gay communities have been at the forefront of the fight against HIV/AIDS. However, people living with HIV/AIDS, sex workers, injection drug users, people with haemophilia, and aborigines have all played significant and worthwhile roles in the community based response to HIV/AIDS. Among all these groups volunteer effort has been outstanding in its extent and commitment.¹

As referred to later in this paper, an Australian AIDS Action Committee (later to be reorganised as AFAO) was formed in August 1983, and immediately met with senior decision-makers such as the then federal Minister for Health, to discuss HIV/AIDS and Australia's response.

AFAO is now the peak body representing community based organisations providing support, education, advocacy and counselling services to those affected by HIV/AIDS and education to all members of the community. In addition, AFAO and its constituent bodies have played a significant role in planning and policy development in Australia.

AFAO comprises representatives from:
- all State/Territory AIDS Councils
- the Australian IV League (AIVL), the peak body of peer injecting drug user groups
- Scarlet Alliance, the peak body of sex worker rights groups
- the National People Living With AIDS Coalition (NPLWAC), the peak body representing and advocating for people with HIV/AIDS in Australia.

In addition, particularly in the smaller States/Territories, the latter three groupings are an integral part of the AIDS Councils. In all States/Territories, all four groupings have good working relationships.

Since 1983, AFAO (or its earlier equivalent) has played a significant role within the community sector in relation to developing close working relationships between all affected communities (such as gay men, people with HIV/AIDS, injecting drug users, sex workers, and people with haemophilia); facilitating and co-ordinating a national response at the community based organisation level; and identification and piloting of new approaches in education.

Much of the success of the community sector in its response to HIV/AIDS can be attributed to its commitment to interventions that were based on and reflected peer group behaviour and attitudes at any given time. This of course is in accordance with the theory of targeted health promotion.

A number of authors have addressed the question of planning HIV/AIDS prevention programs. Valdeserri⁴, for instance, states "target group members should be involved in planning AIDS-prevention programs. By relying on direct input from leaders in the targeted community and by incorporating social science research that addresses

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¹ All groups have had volunteer involvement in proportion to the size of the communities they represent. In some cases, such as in relation to sex worker and injection drug user groups, only a few volunteers have been willing to publicly identify (and represent their peer group at various governmental or official forums), or have believed they had the necessary skills to publicly advocate.

behaviour, mores, and related health and social problems that are of consequence to
members of their community, AIDS-prevention programs can improve their chances of
reaching their intended audiences."

Similar comments have been made by other authors: "(it) requires the involvement of
members of the target group in designing and presenting the message. This use of peer
group members (ideally peer group leaders) also provides greater credibility to the
message, promotes active participation by the target group, and upon evaluation is usually
the most effective."

Australian community based organisations have demonstrated the effectiveness of
this approach on numerous occasions.

3.1 Men who have sex with men

In the early period of the last decade not much was known about the disease, the
exact way it was transmitted, and probable progression. Key members of the gay
community in particular gathered available information, written and oral, and this was the
basis for much discussion, speculation and learning about the disease.

This could be seen as a model of self or peer education. Expertise was developed
that rivalled and in some cases surpassed the expertise of those involved in policy
direction at government level and those who were treating them.

Australia became, and for many programs still is, a world leader in fostering
community behaviour change in the gay community. Programs designed and delivered
by the gay community through the AIDS Councils have been based on detailed risk
education: training in self-management skills related to risk reduction; sexual assertiveness
training for handling high-risk coercions; and an emphasis on health pride, lifestyle
values, and peer group norms of behaviour change. Clearly, very closely aligned with the
Ottawa Charter.

Research conducted both in Australia and overseas clearly demonstrates that AIDS
Councils (or equivalent gay community organisations) are the only organisations in a
position to continue effective HIV prevention programs in established gay communities.

Innovative programs are also being designed and delivered by community based
organisations for men who have sex with men but don't necessarily gay identity. For
example, most AIDS Councils now run "Beats" projects, targeted to the communities of
each State/Territory. The ACON Beats Project is the largest, longest running, and by far

5 Fraser, R., Coates, R.A., Duckett, M., Fanning, M.M. and Remis, R.S.
"Public Health Imperatives of HIV Infection and AIDS in Canada", AIDS: A

6 Dowsett, G.W. "You'll never forget the feeling of safe sex!" AIDS
Prevention Strategies for Gay and Bisexual Men in Sydney, Australia, Paper

7 Beats are public environments where men meet for sexual interaction.
These places include toilets in public parks; shopping centre car-park toilets
and environs; and parks, bush tracks, scenic areas in nature reserves.
The role of community based organisations in HIV prevention

The most developed project of its kind in the world. The success of this project has been acknowledged at the international level. Teaching presentations have been made to the San Francisco AIDS Foundation and the GMHC in New York, and requests for information and assistance have been received from England, Scotland, Germany, The Netherlands and Canada.

Similarly, a comprehensive set of strategies are being trialled by most Councils to reach men who have sex with men in rural areas. A significant number of gay and bisexual men in rural areas are not strongly identifying. Many of these individuals were not being reached by existing programs and, even when contact was made, strategies were not being effective when local peer pressure didn’t support safe sex activities.

So for example, for NSW and Victoria, an entire rural outreach program was developed which involves accessing existing rural social and other networks to provide peer education, assisting the development of new networks in other areas so as to provide support and reinforce peer pressure, training local peer leaders, providing referral and counselling services for isolated men through sympathetic regional health workers and GPs, and replies to classified advertisers in gay/sex magazines, and conducting a low key media campaign. In many ways this description is also apt as a description of the operation of the Tasmanian AIDS Council.

Community based organisations are probably the only organisations with a sufficient understanding of and entree to particularly hard-to-reach groups. For example, because of distrust and anxiety, non-openly gay men require access to be within existing communication channels (eg sex magazines, toilet walls), and existing and trusted social institutions (friendship networks, meeting places such as baths).

Other approaches have included AFAO’s National Peer Education Program for Gay and Bisexual Men. Each State and Territory modified the peer education approach to meet the particular needs of gay and bisexual men, and the social and legal climate in each State. The external evaluation of this Program demonstrated that it was a very effective model to adopt in modifying behaviour. The Program led to the development of peer education programs in every state and territory.

Other specialised programs include projects directed to mature aged gay men (New South Wales, Victoria and Western Australia), women partners of bisexual men (Queensland and South Australia), gay men with intellectual disabilities (Victoria), gay men of non-English speaking backgrounds (New South Wales), and gay injecting drug users (New South Wales).

All AIDS Councils have devoted considerable resources to education and training of health care workers and other service providers. These education programs have addressed inter alia sexuality and homophobia, and have had particular relevance in non-metropolitan areas of Australia to assist in changing the environment and breaking down isolation for some gay men.

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Changes in knowledge, attitudes, behaviour and practice

Australian men who have sex with men have shown a remarkable difference in knowledge, attitudes, behaviour and practice relevant to HIV/AIDS compared with heterosexual men and women. Most of this achievement is generally attributed to the successful programs of AIDS Councils and other community based organisations.

Some illustrative examples of the literature are provided below.

The Social Aspects of the Prevention of AIDS (SAPA) is the most comprehensive and important Australian study of the social and sexual behaviours of homosexual and bisexual men. SAPA consists of a number of major and associated projects conducted jointly by the AIDS Council of NSW and social scientists at Macquarie University. Some eight SAPA Reports have been released, together with six published articles.

The 1986-87 field survey of men who had sex with men in NSW and ACT reported widespread changes to safe sex. The researchers found high levels of correct knowledge but no direct correlation between accurate knowledge of safe sex and the adoption of safe sex practices. Connell et al reported that safe sex is associated with social or sexual engagement in gay community life, with being part of a social network that has safe sex "norms", with high levels of personal contact with the epidemic and, although less significantly, to exposure to media information. Working class men and men from non-English-speaking backgrounds were under-represented in the study sample, although other characteristics of the sample resemble the wider population of adult men.

These research findings were therefore incorporated into the planning and design of subsequent educational programs and interventions, in NSW and other States and Territories.

The Sydney AIDS Prospective Study referred to above found, in a study in 1987 of 420 of the cohort sample, that only 6.3% of the HIV+ men had had unprotected insertive anal intercourse, while 13.5% of the HIV- men had had unprotected receptive anal intercourse. Further investigation elicited that much of this "unsafe" behaviour was occurring in relation to a partner with a known concordant serostatus.

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9 See for example, Australia Market Research, NACAIDS Report 1987.


Campbell et al found in a Victorian study in 1986-87 that 80% of gay men surveyed had adopted safe sexual practices in all circumstances.11

All AIDS Councils conduct specific campaigns promoting safe behaviour among gay and bisexual men on a regular basis. These campaigns are usually evaluated both to measure their effectiveness and to improve future efforts. The Victorian AIDS Council has been the most consistent in long term planning and formal evaluation of its campaigns, although other Councils have usually evaluated their efforts at least on an informal basis. These campaigns represent an impressive amount of imaginative interventions, usually leading to increasing/sustaining safe behaviour.12

Men who have sex with both men and women (and do not identify as either gay or bisexual) have adopted safe sex practices to a far lesser extent than those who identify as gay (of whom a high proportion also have sex with women). In fact, the degree of safe behaviour appears to be related to the degree of attachment to the gay community. For example, Crawford et al13 reported that many men who had sex with both men and women were sufficiently attached to gay communities through their social and sexual practices to be receiving the educational message about safe sex and HIV transmission. Consequently, levels of unsafe sex among these men were low. However, other studies such as those of Bennett et al14 reported substantial amounts of unsafe heterosexual and homosexual sex in their study population recruited through 'beats'.

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The majority of AIDS Councils have now been funded to conduct educational outreach programs through ‘beats’, and some research on useful interventions is being conducted.

Both Connell et al (1990) and Millan and Ross have also suggested that the "newly sexual" - males entering male to male sexual relationships for the first time - require additional and specific programs to increase their safe sex behaviour. During 1990-91, most AIDS Councils were funded under the CAPE program to run specific youth projects - initial evaluations showed some success. However, ACON and VAC are currently the only Councils funded under matched funding arrangements to conduct youth intervention programs. In addition, many of the other AIDS Councils are endeavouring to run specific youth programs with volunteer effort.

This continuing effort directed to youth, despite lack of specific funding, is based on anecdotal reports that most seroconversions in the gay community are occurring in the under 25 age group. For example, in Victoria, Mark Goggin, the Youth Education Officer at VAC noted in a presentation to a conference that: "one in five new HIV diagnoses are among young gay and bisexual men under 25." This statement is supported by reference to the national HIV surveillance report: 82% of new diagnoses, for which a prior negative result was within one year, had unsafe male to male sex as the identified risk behaviour; of all males, 50% were under 29 years of age. Goggin further noted that he estimated there to be 50,000 men aged 16-24 years having sex with men in Victoria; however, only 5,000 were at this stage identifying with the gay community.

HIV incidence

From 1987 to 1990, Australia dropped from 5th among OECD countries to 8th in terms of the per capita rate of cumulative AIDS cases. All the data for 1991 are not yet available, but at this stage it appears that Australia has dropped down the list even more substantially.

15 Davis, M.D., Klemmer, U., and Dowsett, G.W. Bisexually Active men and Beats: Theoretical and Educational Implications. The Bisexually Active Men’s Outreach Project. ACON and Macquarie University AIDS Research Unit, December 1991.


17 The CAPE program was established to fund innovative programs and nationally relevant programs in prevention and education. Grants have a limited term, with the expectation that on-going funding of effective programs will be picked up by States/Territories under the matched funding program.


20 International data supplied by the National Centre in HIV Epidemiology and Clinical Research, February 1992.
According to the AIDS/STD Unit of Health Department Victoria: 

"This is due to a multiplicity of factors, but chief among them must be the lack of high rates of transmission among heterosexual injecting drug users, and continued low rates of transmission among homosexual men and among sex workers. This latter is due in marked degree to the remarkable changes in behaviour that have taken place among members of these groups, as a result of education and changes in social norms."

Australia now differs from most other countries in that HIV/AIDS is found predominantly in gay and bisexual men. The cumulative total of AIDS cases reflect a probable exposure category of male to male sex in 87% of people; 75% of reported HIV infections are attributed to male to male sex. These proportions are decreasing slowly.

The Sydney AIDS Prospective Study (SAPS) enrolled a cohort of 1076 men who had sex with men during 1984-1985. Rates of infection were about 40% at initial enrolment, rising to 50% by 1986. Subsequently, rates of new infection in cohort members dropped markedly, becoming unmeasurable in recent years.

Similarly, the National Centre for HIV Epidemiology and Clinical Research monitors the reports of inner-city Sydney GP practices with high levels of gay clients. New infections as a result of someone engaging in unsafe sex (as reported to the National Centre) have been running at 2/month or 24/year for the last eighteen months.

3.2 Sex workers

Australia has also been the site of some very effective programs designed to foster individual behaviour change in sex workers. Sex worker rights groups have been active throughout Australia in providing information about HIV/AIDS-related issues to workers, and assisting with strategies to improve their safety.

The Australian Prostitutes' Collective (of NSW) was funded in 1985 to provide preventive education regarding AIDS and other STDs. This was the first instance in the world of a sex worker rights group being funded by government ($120,000 in 1985). The rate of STDs in sex workers very quickly diminished and the Sydney STD clinic

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published a survey comparing this change in STD rates with reported extremely high rates of condom usage with clients.26 The authors concluded that the change in STD rates provided an excellent indirect confirmation of the reported increased and high usage of condoms.

Unfortunately, the sex industry is also an example of an area where progress has not been consistent; due to a number of factors sex worker groups have not received continual funding in many parts of Australia. Some continuing work has been done by sex workers on a voluntary basis; for example, Panther in the Northern Territory has operated for five years without government funding. As of early 1992 government-funded sex worker projects are in existence in most capital cities, some funded directly to sex worker groups and others through AIDS Councils.

Changes in knowledge, attitudes, behaviour and practice

A recent study of sex workers was conducted in 199027, involving 280 respondents in NSW and the ACT out of an estimated 1,500 workers currently in the industry in these regions. These respondents had an average of 25 clients a week. The study reported that 97.5% used condoms at work (an increase from a 69.5% result in a survey performed in 1985/86) and 95.4% used them always. The predominant reason given for not using condoms at work was pressure from clients (including payment of extra money, especially to Asian workers).

The authors included reference to a comparison of the private sex lives of these sex workers' compared with a control group of sexually active women who responded to a questionnaire in Cleo magazine. The study reported that sex workers had fewer varieties of, and less frequent, sexual activities, but used condoms more often and more frequently with casual partners.

HIV incidence

Sex work is frequently referred to as a risk behaviour for HIV/AIDS. However, a study of 1100 sex workers visiting Sydney metropolitan STD clinics between January 1985 and 1989 found all to be HIV-negative.28

The sex worker groups are generally acknowledged to be a primary cause for the low rate of HIV infection in sex workers in Australia. In addition, there have been no known cases of HIV being sexually transmitted to or from a sex worker in Australia.29

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3.3 Injection drug users

Injection drug user groups have had greater difficulties in establishing and maintaining stable bases than other community based organisations in Australia. However, the rate of measured HIV infection in Australian users appears to suggest that programs directed towards this group have been very successful in world terms.

One of the earliest groups was that formed by a number of ex-users and drug and alcohol service providers in NSW in 1985, and called the AIDS Drug Information Collective. They developed and conducted a number of outreach programs. Virtually all the initial programs with IDUs were undertaken with relatively little money but enormous amounts of commitment and volunteer effort. For example, users said they wanted a needle/syringe exchange service to facilitate safe needle use. Members of the Collective organised such a service without official funding, and actually illegally at that time. The relatively smooth running of a couple of unofficial sites for nearly a year and data showing an increase in the rate of infection of NSW injection drug users provided the impetus for official authorisation of needle/syringe exchanges.

Similar initiatives were undertaken in most States and Territories, although sometimes legislative change was a long way behind government policy: for example, South Australia only changed the relevant legislation allowing legal possession of needles and syringes from a needle/syringe exchange in late 1989, two years after the government had been funding such exchanges.

In other cases, policy does not yet reflect the national strategy: as of February 1992, Tasmania has no legal needle/syringe exchange scheme.

The needle/syringe exchange program throughout Australia has expanded rapidly since its introduction: it is currently the most geographically widespread in the world, and the Prostitutes Collective in Victoria operates the third largest exchange in the world, in terms of number of needles/syringes exchanged annually. Use of this latter exchange is not limited to those in the sex industry: it is accessed by a wide range of users from a variety of backgrounds and social positions.

As an example of the growth within NSW: from a service funded from the pockets of Collective members, needle/syringe exchange schemes have grown to the point where there are currently 500 participating pharmacies and over 100 public sector exchange outlets. The total budget from the AIDS Matched Funding program for the NSEP of NSW for 1990/91 was approximately $4 million. This funding covers 32 primary NSEP outlets (including 2 community based organisations, and 2 other non-government organisations), and over 100 secondary outlets in a range of health service delivery settings.

Throughout Australia, although the majority of needle/syringe exchanges are funded to government health services, many of the most successful needle/syringe exchange schemes (in terms of behaviour change on the part of clients) have involved community based organisations, either user groups, sex worker groups, or AIDS Councils.

Unfortunately, in early 1992, local police raided the Collective. This involved closing the exchange, and strip searching staff, volunteers and service users. They stated that they were "making it clear that needle exchanges are not exempt from laws relating to drug possession". This police action has had adverse effects not only on the PCV needle exchange; it has affected other Melbourne exchanges and the other services provided by the PCV.
This success is attributed to the fact that community based organisations are usually in a better position than government agencies to promote peer support and an accepting environment.\(^{31}\)

**Changes in knowledge, attitudes, behaviour and practice**

As reported in the HIV incidence section below, Australian rates of infection in injection drug users are substantially lower than in other countries. This result is attributed in part to the early establishment of needle exchange schemes and the funding of peer groups.\(^{32}\) One result has been the relatively high rate of return by international standards at most such sites, and the high proportion of users exchanging needles for more than themselves. Peer- and community-based needle exchange programs feel they have demonstrated that they can assist users to form attachment to a community which provides support for safer behaviour.\(^{33}\) Groenhout believed that the majority of clients of community based organisation exchanges demonstrated a fast decrease in high risk using behaviour.

By contrast, among IDUs attending treatment agencies there appears to be considerable discrepancy between knowledge and behaviour; Wolk et al.\(^{34}\) report perceptions of low personal risk and frequent HIV risk-taking behaviour.


\(^{32}\) Various other reasons than the early availability of needle/syringe exchanges have been advanced to explain the low incidence of HIV infection in injection drug users, including low numbers of users, non-sharing patterns of usage, and containment of HIV within the gay community due to gay users only largely sharing with other gay users.

However, examination of these premises does not seem to support such suppositions. For example, Wodak reported at the 3rd International Conference on Harm Reduction on a survey of all needle/syringe exchanges on their estimate of client numbers. These totalled to estimates of 200,000 to 300,000 users in Australia (in contrast with more usual official estimates of 30,000 to 50,000).

The ANAIDUS study found that in statistics collected in 1989, more than 50% of respondents had shared needles within the previous twelve months. The 1990 statistics showed improvement, although 15% of Sydney users continued to share. Similarly, the Gay Injecting Drug Users Project Needs Assessment did not find that gay IDU were most likely to share with other gay IDU.

\(^{33}\) Ibid.

HIV incidence

The spread of HIV among injection drug users has been remarkably less in Australia than in any other country. Carballo and Rezza\textsuperscript{35} report that injecting drug use is a primary risk factor for the spread of HIV/AIDS in many countries. For example, in Europe in 1989 approximately 27% of all reported AIDS cases were related to a history of drug injecting; in selected regions drug injecting accounted for as much as 50-60% of all cases of AIDS. These figures have continued to increase since 1989.

By contrast, the ANAIDUS study has documented a rate of HIV infection of less than 5% in Australian injection drug users, with the preponderance of HIV infection in gay IDU.\textsuperscript{36}

4. WORKING IN PARTNERSHIP WITH GOVERNMENT

Members of community based organisations are included on Ministerial Advisory Committees on AIDS at the federal level and in most states. Their contribution has frequently been acknowledged by government improving the quality of advice received and hence the subsequent quality of program design and delivery.

The community based organisations, particularly working through AFAO, have made significant contributions to a range of policy and legal issues raised by HIV/AIDS.

AFAO has developed a comprehensive range of discussion papers on issues including:

* Implementation of the National HIV/AIDS Strategy
* The Law and Practice relating to Death and Dying
* Mainstreaming
* Treatments
* Rapid HIV testing
* Entry of HIV infected applicants for permanent residence
* Responses to IGCA Discussion papers on
  * HIV/AIDS and Anti-Discrimination Legislation
  * Legislative approaches to Public Health Control of HIV-Infection
  * Legal Issues relating to AIDS and Intravenous Drug Use
  * HIV/AIDS Prevention, Homosexuality, and the Law
  * Employment Law and HIV/AIDS
  * HIV/AIDS and the Sex Industry.

Members of community based organisations were also integrally involved in the process leading to the development of the policy discussion paper, AIDS: A Time to Care, A Time to Act. Toward a Strategy for Australians (Commonwealth of Australia 1988), in the subsequent series of public hearings, and finally in the finalisation of a national AIDS strategy, National HIV/AIDS Strategy (AGPS 1989).


\textsuperscript{36} ANAIDUS, op cit, 1991.
The role of community based organisations in HIV prevention

This document is, in many ways, a consolidation of existing practice and an elaboration of the direction taken since the early years of the epidemic. The national strategy is essentially based on community consultation and participation, rather than one of coercion and imposition.

Perhaps in some way as an offshoot of multiculturalism, governments in Australia have generally operated with an acceptance of the notion of multiple communities within Australian society. AIDS has been seen as a gay issue, however it has not lead to the same degree of overt public homophobia as has been evident in the USA and UK. Instead, AIDS is seen as a major problem and some specific communities have been funded to assist in resolving the problem.

Thus governments have adopted a direction of expecting affected communities to take a leading role in prevention programs delivered to their constituency, eg. gay communities through the AIDS Councils are leading the design and delivery of education programs directed toward gay and bisexual men. Similarly, sex worker groups have taken a leading role in designing and delivering prevention programs directed towards their constituency.

This overall policy direction has been promoted at the international level by the World Health Organisation as exemplary of an effective response; Australia's HIV incidence levels compared with similar countries are now demonstrating the policy worth of integrating community based organisations in the national response to HIV/AIDS.

However, many community based organisations are increasingly concerned that their past effectiveness in HIV prevention may lead to complacency among funding authorities, and subsequently insufficient resources to continue programs to assist affected communities enable and sustain safe behaviour.

These concerns are highlighted by reports such as that of the European Centre for the Epidemiological Monitoring of AIDS, which recently noted that the proportion of cases of AIDS and HIV infection diagnosed in male homo/bisexuals had been decreasing since 1984 but in 1990 and 91 had commenced rising again.

5. FACTORS FACILITATING AND HINDERING THE EFFECTIVENESS OF COMMUNITY BASED ORGANISATIONS

Perhaps the major factor influencing the effectiveness of community based organisations was the swiftness of their response to HIV/AIDS.

In contrast with most diseases, especially the emergence of unexpected or new diseases, much of the initial response to HIV/AIDS was organised by affected groups themselves.

Gay publications such as the Star Observer carried substantial coverage and discussion of HIV/AIDS from June 1981 onwards, the Sisters of Perpetual Indulgence distributed a leaflet on safe sex in 1982 (it includes mention of PCP and KS), and the formation in 1983 of the AIDS Learning Exchange and the Green Monkeys were initiatives of the gay community.
In NSW, an AIDS Action Committee was formed in May 1983 by members of the gay community, with a predominantly educational and political focus. The Victorian AIDS Council (VAC) was formed following a public meeting of members of the gay community in July 1983. At the 9th National Gay and Lesbian Conference in August 1983 the Australian AIDS Action Committee was formed (later to be reorganised as AFAO), based on a coalition of representatives of AIDS Action Committees from most States and Territories.

Immediately following this conference, the Australian Committee met with Dr Blewett, the then Minister for Health, to discuss HIV/AIDS and Australia's response.

This early organisation and commitment therefore provided government with a point of contact with the affected communities. It should be noted that this organisation occurred, in some cases, in spite of governments, eg. homosexuality was still illegal in NSW until 1984, and still is in Tasmania.

The second major factor facilitating the effectiveness of Australia's community based organisations has been the early nature, and level, of government funding provided to community based organisations, especially when compared with similar countries' responses. For example, in the ACT the majority of the AIDS matched funding from the federal and territory governments goes to community based organisations; and the Victorian AIDS Council received federal funding when only a few cases of AIDS had been reported in Victoria.

Additionally, at the Federal level and in most States, community based organisations have worked closely with government in policy and program development. This followed initiatives such as those mentioned above, where the affected communities had demonstrated very early in the epidemic their ability to organise, and to design and deliver effective education and support programs. One example is provided by the Rubba Me campaign in NSW in mid 1985: the NSW Health Department withdrew funding because of the explicit nature of the material; however, the Gay Counselling Service and the Bobby Goldsmith Foundation then provided funding, and evaluation of the campaign showed it to have been exceptionally effective. In later years, the NSW Health Department provided funding for similar explicit campaigns.

Members of community based organisations believe that the eventual close cooperation between governments and community based organisations, at the national level and in the majority of States and Territories, has enabled community based organisations to impart some sense of urgency and a proactive approach by government. Australian community based organisations have been involved in policy forums at the highest levels and this is generally acknowledged as ensuring that Australia's response to HIV/AIDS has been one of the most effective in the world.

However, governments have been reluctant to support community based organisations in some States by such actions as decriminalising or legalising homosexual sexual contact, decriminalising prostitution, making sexuality a ground for offence under anti-discrimination legislation, or decriminalising the possession of injection drug equipment.

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37 Carswell, P. Personal communication, December 1991.
In those States and Territories where consultation has not occurred with the community based organisations, the response to HIV/AIDS could generally be seen to be inferior than in those States and Territories where consultation has occurred and harmful laws have been removed.

Funding allocations at national, state and local levels to community based organisations have varied greatly. Some programs have been well funded, other not. Lack of funding has been most marked in the prevention area. Examples include relative lack of funding to outer area and regional programs, peer education, and programs targeting people with HIV.

Compared with similar countries, Australian governments and health authorities have, generally, strongly supported community based organisations in the conduct of a range of education and support programs. Education programs have tended to be relatively explicit and, arguably, far more effective. However, when community based organisations have endeavoured to run education programs outside a very narrow definition of their target communities, and hence, challenge the taboos of the wider community, the support has often been withdrawn.

Examples include the Victorian Government failing to support the recent Youth Education campaign of the Victorian AIDS Council which addressed the issue of experimental sexuality among young people, and the direction by the South Australian Health Commission that no HIV/AIDS material of a sexually explicit nature was to be on show to older teenagers using youth centres.

Despite these problems when community based organisations move outside a narrowly conceived "brief", Australia is widely acknowledged to have had many outstanding successes in education.

Generally, innovative and effective programs have occurred at the individual and community level in those areas where peer group members have been integrally involved in the design and delivery of programs. Other programs directed to individual and community level behaviour change have been less effective.

The programs have basically only been useful when the target group has had control over the language used, the explicitness of the material and the media used for transmission of the message.

However despite the reference to government support, some current legislation could be used to constrain the effectiveness of advice. For example, since HIV is transmissible in situations sometimes involving some illegalities, educators advising on safe sex or injecting drug use might face general aiding and abetting charges in some circumstances.
In some legislatures, the potential problems are very clear: in NSW, for example, the Crimes Act appears to prohibit the provision of safe sex advice for young men having sex with men; in Western Australia, there are provisions which inhibit safe sex education in schools; and in Tasmania, all sexual contact between men remains illegal.

Other problems have arisen in regard to the explicit nature of some educational material: some pamphlets (eg. Safe S/M) have received classifications from the Censorship Board that require them not to be generally displayed or distributed. This of course precludes easy access by target group members to necessary information rate (all the limited distribution material rates very highly with their target audience when they actually see it).

In addition, police prosecution practices often cut directly across public health objectives. To give one example, the availability of pamphlets providing information about HIV infection to the clients of prostitutes, could be used as evidence that premises are being used for the purposes of prostitution. Similarly, the fact that a woman is in possession of a large number of condoms has been used in NSW this year as evidence that she was working as a prostitute. The above, and other practices, create a situation in which men and women who work in the sex industry but wish to avoid prosecution, are best advised to avoid having condoms or information about sexually transmitted diseases in their possession or on their premises.

6. INTERNATIONAL COMPARISONS

Moerkerk and Aggleton have typified official responses to HIV/AIDS in Europe into four categories:

The pragmatic response of Norway, Denmark, the Netherlands and Switzerland. The emphasis is on information and education, not on coercion but on planning, evaluation, pragmatism and consensus.

The "political response" of Britain and the Federal Republic of Germany. Here the law is seen as an instrument by which human behaviour can be regulated and the epidemic controlled.

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38 Crimes Act 1900 s78(Q)(2): Any person who solicits, procures, incites or advises any male person under the age of eighteen years to commit or to be a party to the commission of an act of homosexual intercourse, or an act of gross indecency, with a male person shall be liable to imprisonment for two years.

39 Law Reform (Decriminalisation of Sodomy) Act: "It is unlawful to promote or encourage homosexual behaviour as part of the teaching in any primary or secondary educational institution. Penalty: imprisonment for one year."

The biomedical response of Belgium, France, Spain, Italy and Greece. Established medical institutions have determined official policy and interventions with little participation from community groups.

Emergent responses in those countries where HIV disease has only recently been identified as a serious concern - for example, the eastern European states."

Using this framework, Australia appears to fall into the "pragmatic response" category with some overtones of a "political response".

Some illustrative examples are provided below of the role and functioning of community based organisations and epidemiological data related to countries in these categories.\(^\text{41}\)

The information illustrates that many of the directions in Australia that we take for granted are special in world terms and have been very much to Australia's advantage. The Director of the W.H.O.'s Global Program on AIDS said of Australia: "Australia's response to the AIDS epidemic is a model for others... a model of how to act aggressively and in a co-ordinated fashion to address the many issues involved."\(^\text{42}\)

However, others are not sanguine that this positive approach will continue: "Australia has displayed a similar capacity for narrow-mindedness, for bigotry, for social control, for intolerance and conservatism to that found in most countries. Australians have not shown themselves to be particularly broad-minded or generous, particularly sensitive or well-informed, particularly tolerant or accepting of HIV infection or its sequelae.....the multipartisan political support for Australia's response to HIV infection is fragile with some law-makers, sniffing an ungenerous political wind, arguing for a more punitive, judgemental and atavistic set of policies."\(^\text{43}\)

If Baume is correct, the Australian community as a whole will suffer immensely.

The comparative data shows that Australia's early rates of infection were relatively high at the time when the transmission modes for HIV/AIDS were not well known, and many had become infected prior to the characterisation of HIV. In the intervening period, our national strategy has centred upon prevention strategies in partnership with community based organisations, and our relative performance compared with comparable countries is improving steadily. Australia's rate of reported AIDS cases in 1985 was 7.1 per million of population, in 1990 it was 35 per million of population.

\(^{41}\) Epidemiological data drawn from:
Australian HIV Surveillance Report, National Centre for HIV Epidemiology and Clinical Research.


One of the major differences in the Australian response has been the promotion of a community response to HIV/AIDS rather than an individual based response. The concept of community development and peer support is of course integral to the Ottawa Charter model of health promotion.

By contrast, many other countries have either denied the existence of a gay or other target group community, or concentrated on individual responses.

One important difference in responses has been the degree of involvement of community based organisations in program design and delivery.

An example of the "pragmatic response" is provided by the Netherlands. They were the first country to initiate official needle/syringe exchange schemes, although these are still only found in major centres such as Amsterdam and Rotterdam. Gay and lesbian organisations received funding from the Netherlands government prior to the advent of HIV/AIDS; this funding has been increased to assist the gay community response to HIV/AIDS, although to a lesser extent per capita than is the case in Australia. The rate of reported AIDS cases in the Netherlands in 1985 was 4.6 per million of population, in 1990 it was 27.1 per million of population.

Community based organisations have never been involved in HIV/AIDS related decision-making in the United Kingdom (political response): this is often postulated as one reason for the complacency about HIV/AIDS exhibited by most decision-makers, and the relative lack of effective HIV/AIDS prevention programs. McKenna reported that "on average a gay man tested HIV antibody positive every six hours in 1990".44 The rate of reported AIDS cases in the UK in 1985 was 3.7 per million of population, in 1990 it was 17.9 per million of population.

The United States could be seen as falling into the category of "political response". The rate of reported AIDS cases in the USA in 1985 was 39.7 per million of population, in 1990 it was 168 per million of population.

There are still no officially funded needle exchange schemes in the USA (although a few community based organisations unofficially provide these services on an outreach basis). Indeed, workers distributing clean needles with the permission of the New York Health Department were arrested last year and charged in court with illegal activities. Subsequently, exchange schemes in most locations have become even more clandestine and limited. Government funding to HIV/AIDS community based organisations remains pitifully low by Australian standards, and, due to the political and social climate, involvement by HIV/AIDS community based organisations in policy making is sporadic and limited. New HIV infections in the United States are strongly tinted to class and ethnicity factors: minority groups and the poor are being devastatingly affected.

A "biomedical response" is exemplified by France, where community based organisations have played a very limited role and where substantially higher rates of transmission have occurred in men who have sex with men relatively late in the epidemic. In France, the rate of infection in 1985 was 10.3 per million of population, in 1990 it was 63.8 per million of population.

The second major difference between countries involves the production and distribution of targeted educational material.

Both the USA and Canada have allowed much less explicit and erotic HIV/AIDS educational material than has been produced in Australia with government support. Community based organisations advise that research findings which validate the necessity of these approaches have been ignored/rejected by their governments even when fully sanctioned by the relevant health departments, and they produce and distribute such material in a limited way and only with private fundraising.

A third major difference concerns the easy accessibility of condoms.

Most AIDS Councils in Australia have for a number of years aimed to ensure that educational materials, condoms and lubricant are freely available and promoted in all sex-on-premises venues. AIDS Councils see sex-on-premises venues as valuable sites for accessing bisexual and less strongly identifying gay men such as men from non-English speaking backgrounds.

However, this is not necessarily the case in other countries. For example, very few steam baths in Western Europe provide condoms: no steam bath in Germany is reported to provide condoms, and those in the Netherlands sometimes have them available but only in a slot machine if the correct amount of money is inserted. Lube is not available.

Sex worker groups in other countries receive very little government funding: according to a consultant to W.H.O. on sex industry issues (Julie Bates), the only funded sex worker rights groups that she is aware of are in California ($100,000 in 1988/89); the Deutsche AIDS Hilfe in Germany which received minor funding in 1989/90 (and continuing); the Scottish Prostitute Education Project group which received minor funding in 1991; and limited funding to Kabilikut in the Philippines, another group in the northern Philippines, and a group in New Zealand (who receive insufficient funding to allow a full time salary for the co-ordinator). Empower in Thailand has received direct funding from W.H.O.

Apart from the Australian experience, the only known sex worker group represented on government advisory bodies is one in the Netherlands, where the Dutch Ministry for Emancipation of Minorities provides a small grant to a sex worker rights group to assist them provide representation on government committees.

No IV user group (as distinct from interested and supportive professionals) is known to be involved in setting government policy in any other country.45 Two user groups in the Netherlands receive government funding to conduct needle/syringe exchange; a few other countries have functioning user groups who operate with private fund raising (New Zealand, England, Germany, the United States, and Nepal).46

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45 Personal communications, December 1991.

46 Advice from the First World Meeting of Injecting Drug User Groups, Melbourne, 1992
7. IMPLICATIONS OF MAINSTREAMING

The general direction towards mainstreaming in Australia has a number of important implications for both the partnership between government and community based organisations, and the effectiveness of Australia's response to HIV/AIDS.

First, mainstreaming will lead to devolution of funding and decision-making about programs to state, regional and local levels.

One aspect of concern that arises is that our health system is still very much hospital focussed and curative/treatment oriented rather than community based and preventive. This is particularly so in the non-metropolitan areas and regions. To the extent that services are able to move funds from preventive services to inpatient hospital services, this is likely to lead to a lessening of emphasis on HIV prevention.

An additional obstacle is caused by the fact that many of the HIV/AIDS community based organisations have been established and are conducted from within the communities of those most at risk. It is abundantly clear that these same communities remain marginalised by and large, particularly so in non-metropolitan areas. The likelihood of these groups maintaining their significant and essential contribution to the AIDS response is being lessened, and their contributions are being denied in many regional and local areas.

These concerns are highlighted by the experience with HIV prevention work in Britain. The UK Department of Health gave health authorities a total of £137 million pounds for regional responses to HIV/AIDS in 1991. The Department said it "expects at least 20 million pounds of this sum to be spent on HIV prevention work."

However, spending breakdowns of HIV prevention work reveal that barely a fraction of this sum is targeted at gay men. This is occurring with senior Departmental officials being quoted as: "extremely concerned" and "we're aware of the reluctance of many health authorities to tackle HIV prevention work in the gay community, but our feeling is that it's too important an issue to pussyfoot around", and despite explicit guidance being given to health authorities over how money allocated for HIV/AIDS should be spent. This guidance includes strong recommendations to set up "community-based initiatives to target population groups at risk of HIV infection".

One way of addressing these issues is for the federal and state governments to publicly and strongly endorse the involvement of community based organisations at regional and local levels.

However, guidelines and requirements not explicitly tied to funding are unlikely to be sufficient.

Under the "mainstreaming" approach to HIV/AIDS treatment and prevention services adopted in NSW, each area or region sets its own priorities within agreed guidelines. The Eastern Sydney Area Health Service, which covers 40% of the total Australian figures for people with HIV/AIDS, provides an astounding example of lack of

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inclusion of any community based organisation including ACON or PLWA(NSW) in decision-making and resource allocation within the area.

AFAO recommends that it should be a condition of funding that community based organisations be involved at every level in decision-making and resource allocation.

It must also be acknowledged that "creating a supportive environment" and "strengthening community action" (essential components of an effective prevention approach) can not be adequately addressed from outside the targeted community. Rather, the communities and their organisations must be directly resourced to do that work.

Second, a mainstreamed approach means that AIDS Councils and other HIV/AIDS community based organisations have to effectively reach decision-makers in a much larger number of authorities and organisations. They will therefore require funding to a higher level than currently just to address the additional work required by mainstreaming responsibilities.

Third, experience has shown that the community based organisations are particularly effective in communicating risks of unsafe behaviour and alternatives. However, governments have been wary of endorsing or even condoning some of these important campaigns apparently for fear of being seen as possibly promoting homosexuality or drug use.

The generalist agencies have never effectively addressed these issues, and on their current performance are unlikely to do so.

In addition, funding bodies sometimes appear to prefer to fund generalist agencies rather than community based organisations, despite the latter's documented successes, or to fund community based organisations at a level totally unrelated to the expectations of the target audience for that position. This tendency also will need to be explicitly addressed.

A fourth concern is raised by the experience of many AIDS Councils with many regional areas that deny that gay men, users or sex workers exist in any significant numbers in their area, and therefore refuse to support HIV prevention or support programs targeting these groups.

The major argument accepted by health departments for mainstreaming treatment services is that HIV/AIDS manifests itself as a variety of medical presentations which require a range of subspecialty expertise, and insufficient funds are available to establish multidisciplinary HIV/AIDS specialist teams in every major region and location. That is, the skills of the infectious diseases physician alone are not sufficient to ensure high quality state-of-the-art treatment; an AIDS patient with cancer should be treated by an oncologist, an AIDS patient with neurological problems should be managed by a neurologist, and these general services are already available in many more locations than existing HIV/AIDS units.

A valid argument can thus be made that a cost-effective acceptable range of services for the expected number of people with HIV/AIDS in the next few years can only be delivered by moving to mainstreaming.
These arguments are essentially irrelevant when applied to HIV/AIDS prevention services, as expertise in HIV/AIDS prevention rests almost exclusively with the community based organisations. This expertise in designing appropriate messages, designing appropriate vehicles for those messages, and providing a sympathetic and sensitive environment to enable and sustain behaviour change can only be demonstrated by community based organisations.

It may be argued that for reasons such as economy of scale, specialist HIV/AIDS prevention services should be replaced by generic services, but this would inevitably be accompanied by a loss of specificity in programs and, likely, a loss of effectiveness. Hence mainstreaming in these circumstances would not be cost effective.

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