

extremely marginalized and poor in resources. Work among street kids in developing countries, such as the Karate Kids project in Haiti, Mexico, Brazil, etc., depends upon an external agency, but an agency which sees the kids as partners rather than as subjects of intervention. The basis of the project is a cartoon that teaches children the importance of using condoms for prevention against HIV, and is built upon a recognition that 'key aspects of the common culture of the children depicted in Karate Kids are economic marginalization, the formation of youth gangs in the face of family breakdowns and the misery of slum life, mistrust of authorities, and strong emphasis on the basic human values of friendship, courage and ingenuity'.⁴⁸ Most important, the approach recognizes that preaching to street kids about the evils of sex and drugs is counter-productive, and that they require to be empowered in ways which will enable them to better control the effect of commercial sex and drug use. A somewhat different approach has been adopted by the Family Health Trust of Zambia which works through schools, and has helped establish 1500 'anti-AIDS clubs' geared at prevention of HIV and other STDs throughout Zambia, in effect through promoting sexual restraint.

Peer education will have different messages and different targets in different societies. Even translating the term 'HIV/AIDS' into non-Western languages is difficult; as one Native American wrote (in 1993):

It is only within this last year that AIDS was given its equivalent name in the Lakota Sioux language. 'Kuja Futa Tanka', which although difficult to translate into English, means something like 'to have an illness or to be unbalanced, anything that is inflexible and unbendable like a steel rod and greater than, in that two is greater than one.'⁴⁹

This should remind us that the language of both AIDS and its control is that derived from Western concepts or virology, immunology, and psychology. This point is amplified in a study of Kenya by A.J. Fortin:

The language of AIDS in Africa is one derived from the West... It speaks in Western symbols and with a voice that was born from that cultural cosmology. It is not indigenous to Africa and thus is blind to the African world of meaning. For example, there are cultural practices, traditional rituals including a host of communal eating and drinking practices, that seem to be coming under what may be called the negative influence of AIDS

fundamental to community bonding and the meaning of social life. Yet they are all falling victim, justifiably or not, to both the negative impact of Western inspection and the public's fear of contracting the AIDS virus.⁵⁰

In similar ways, the need to preserve 'community bonding and the meaning of social life' was faced by groups in the West, as in the case of gay men whose practices came under intense surveillance and in some cases increased regulation because of the epidemic.

While the actual responses will be very different, in both of these examples there is a need for educational interventions to be built by the communities involved, and to be empowering of them, rather than viewing them as passive recipients of education messages dispensed by external experts. The very understandings of HIV/AIDS need to take account of the social, political and cultural histories of particular communities, in particular their relationship to Western discourses and domination; for Australian Aborigines to understand AIDS as part of a threat from outside that 'brings with it the corruption of culture, the fragmentation of community, the spectre of genocide'⁵¹ is important to their being able to accept the seriousness of the problem and develop appropriate responses.

But education can have wider goals than prevention interventions. It can also address general ignorance and prejudice about AIDS, and thus shades into advocacy and support for those who are infected. Many community organizations accept a role in general education, and may sometimes be responsible for large-scale campaigns that elsewhere are the province of health departments. Thus one development agency, AHRTAG (the Appropriate Health Resources and Technologies Action Group) funds several NGOs in key developing countries to issue local versions of the newsletter *AIDS Action* as part of a general commitment to increasing levels of awareness about AIDS. Some CBOs such as Patronato de Lucha Contra el Sida (PLUS) in the Dominican Republic are supported by governments to operate AIDS information 'hotlines'.

Advocacy

At one level, most of the work of AIDS organizations can be seen as advocacy; other than one-on-one care, support and education programs require constant advocacy, whether this be understood as influencing

increasing public awareness. The complaint often heard from grass-roots volunteers that their organizations are 'too political' overlooks the harsh reality that it is only through political action that the basic requirements for services can be provided. Advocacy is needed to put the issues raised by AIDS on the political agenda, to influence the response of governments to those issues, to win funding and support for initiatives and programs desired by community groups and to protect against discrimination and neglect. But advocacy is also needed for groups merely to be able to provide care and education, as shown in the case of ARRELS 'a typical AIDS service organization' in Palma de Mallorca, Spain. Because the regional government claimed that ARRELS was promoting homosexuality it denied it not only funding but also the status of an association of 'social interest', important for it to be able to function.⁵²

More than most diseases, AIDS carries with it the threat of massive discrimination (and discrimination which is sometimes extended to anyone perceived as being at risk of AIDS: straight men have been bashed because they are seen as 'AIDS-carrying faggots' and sex workers frequently attacked as responsible for the spread of the epidemic). To ensure access to appropriate services and adequate government attention for the epidemic therefore involves considerable advocacy, and almost all CBOs find themselves engaging in constant interlocution with health officials, hospitals, welfare offices etc. As the Italian group LILA (Lega Italiana per la Lotta contro l'AIDS — Italian League for the Fight against AIDS) has observed 'the list is never-ending', giving as examples: 'seropositive children not admitted at nursery or primary schools; young people who are refused employment because the medical examination showed that they were seropositive or simply because they had refused to undergo the serological examination provided for by law; workers who have been dismissed with the threat of making their seropositivity condition public knowledge; the former drug addict to whom hospitalization in dental clinics or normal dental practices are refused; the patient hospitalized in an orthopaedic department who, without knowing it, has undergone the seropositivity test and then has been discharged without being operated on; the professional who cannot go to work in Sardinia because the local health service refused his dialysis because of his declared seropositivity...'.⁵³

These examples underline the larger human rights dimensions of the AIDS epidemic. More than most diseases — there are echoes of this in the history of syphilis and leprosy — AIDS has created reactions which lead to gross violations of human rights, including imprisonment, deportation,

AIDS workers, along with gay activists, have been murdered in Mexico and Guatemala, and there are reports that young Burmese girls have been forced into prostitution in neighbouring Thailand, become infected, and have then been killed on their return home.⁵⁴ Positivity is often used as a reason to restrict movement across frontiers (which may mean denial of refuge, of education or of family reunion), and in some cases to prevent the right to marry.⁵⁵ In many countries whole groups of people, most often homosexuals and prostitutes, have been attacked because of their alleged link to AIDS.⁵⁶ Most AIDS organizations have had to take up human rights issues as a logical extension of their work, whether it be concern with police keeping records of people who are (or are suspected of being) positive, or discrimination in housing, employment and health care. Some organizations develop special programs to protect those most likely to be affected by discrimination and least able to fight against it: prisoners, street kids, sex workers, drug users etc.

In many of these cases, AIDS organizations act as mediators between individuals and the state, and this is an important element of the service function of community organizations. But human rights means more than recognition of individual civil and political rights, which is how it is often understood in liberal societies; I understand human rights to encompass the full spectrum of social and economic rights as envisaged in Article 28 of the Universal Declaration of Human Rights: 'Everyone is entitled to a social and international order in which the rights set forth in this declaration can be fully realised'.⁵⁷ Thus AIDS advocacy also requires the articulation and assertion of general policy positions on a whole range of care, treatment and support issues, on topics ranging from access to information (both therapeutic and preventive) to respect for confidentiality and unconventional family structures.

There is often a perceived tension between being a service and an advocacy organization. The first requires organizations to work closely with the institutions of the state, the second may demand direct confrontation of those same organizations. The reality is more complex, for advocacy takes many forms, some of which are quite consistent with a close relationship to the agencies of the state. But while advocacy is clearly a role of all community-based organizations, what characterizes the 'AIDS movement' is the extent to which their work is characterized in quasi-military terms as a 'struggle', a 'war', a 'battle'. AIDS, as has often been pointed out, is the most politicized of diseases. Groups like ACT UP (see later sections) came into being because of a perception that the existing community organizations were too timid in their approach to the

causation, as in the words of an obituary from the San Francisco *Bay Area Reporter*: 'Governmental inaction, corporate greed and the queer-hatred of the US citizenry have murdered one more of our warriors'.⁵⁸

Advocacy can involve representation within the organs of the state as much as it does attacking these same institutions on the streets. AIDS is remarkable for the extent to which governments have acknowledged affected communities, and accorded them representation on the committees and in the agencies which make policy. In some countries this has meant official representation on National AIDS Committees, and the best example of this is probably New Zealand, where the original Council (only appointed in 1988) included two infected people and representatives of gay, sex worker, user, Maori and Polynesian groups. (The Council was, however, abolished by a more conservative government in mid-1993.) Where this sort of recognition is less clear one often finds very close and on-going access to at least some branches of government; even during the Reagan and Bush Administrations, AIDS organizations had close contact with government via their links with sympathetic members of Congress, usually representing constituencies with well mobilized gay populations, such as Ted Weiss in New York or Henry Waxman in Los Angeles. Thus GMHC runs a Citizens AIDS Lobby which is effective at both city and state levels,⁵⁹ and AIDS Project Los Angeles has a sizeable 'public policy' section, which not only maintains its own lobbyist in the state capital, Sacramento, but also encourages considerable grassroots lobbying of state and federal legislators by its members and supporters. The major AIDS organizations in the US constitute what is sometimes called 'the AIDS lobby' which has become a not inconsequential player in domestic politics; its power was reflected in the attention Clinton paid to AIDS issues during his 1992 election campaign (some would say far more than he did once he was elected).

Yet where governments seek to stop certain forms of AIDS education, or limit access to certain drugs, or are unable to prevent (or are themselves responsible for) discrimination, the everyday work of AIDS care and support can become a direct challenge to the state. As already suggested, the language of safe sex education very easily becomes an arena of conflict between community-based organizations and governments. Where the distribution of condoms or needles is illegal, prevention practices can easily be criminalized, and peer education becomes an act of defiance, as in the United States where a number of groups have illegally distributed clean needles and where one activist, Jon Parker, has been arrested thirty

controversial in the United States, with some minority communities supporting the argument that it is likely to increase drug use, and hence should be opposed. It has been a subject of continuing controversy in New York City, despite that city's very high rate of needle-transmission, and community organizations advocating needle exchange have encountered on-going obstacles.⁶¹ In 1993, at least one court case in California was in process which was testing the constitutional ability of the state to ban exchanges which, it was argued, are required by the necessity of stopping the spread of HIV. The city of San Francisco has not been prepared to wait for the outcome of such cases; early that year the city, after strong pressure from the San Francisco AIDS Foundation and other groups, declared a local emergency to enable it to establish a city-funded needle exchange program.

Nor is advocacy confined to the agencies of the state. A number of AIDS organizations have developed programs aimed at the workplace, concerned both with prevention education and protection of those already infected. This has been a concern for both developing and developed countries; yet whereas most developed countries have certain legal protections for workers — as well as access to health care — this is not the case for poorer countries. As one speaker at an American seminar said: 'First of all let me state how lucky you are in the US to have the laws you have. Labor law in Zambia is simply there to ensure that the original contract between each individual worker and his employer is respected. For example, if I am employed and my letter of appointment says that termination shall be by one month's notice, that is all that the labor law is there to protect. It is difficult to ask for positive discrimination for AIDS people.'⁶²

Workplace programs have to address questions of discrimination, fears of transmission, and the possibilities of combining support for HIV positive people with their right to continue working, very often in situations where both economic and political structures mitigate against any respect for even the concept of workers' rights. Programs need to target both employers and workers; thus the Hong Kong AIDS Foundation has distributed its booklet 'AIDS in the Workplace' to managers, while in Brazil ABIA has developed a number of projects aimed at reaching both employers and workers. In the case of one large mining company in Amazonia, whose migrant workers are perceived as at considerable risk for HIV, a pilot education project made use of the sound system of the railway which carries workers to the mines to broadcast prevention messages.⁶³ Such programs are often particularly useful in

to work with the groups most disempowered by the sex/gender order.

There is not much information on the role of trade unions in AIDS campaigns — they are rarely mentioned in the literature, which may reflect the American bias of so much HIV prevention and support work — but in some countries such as South Africa the union movement has been an important resource for organizing the provision of AIDS services.⁶⁴

Most AIDS organizations devote considerable attention to fund-raising, and this is often perceived as no more than necessary support work, not central to the major goals of the community sector. Certain sorts of fund-raising can, however, play a role in both heightening public awareness and community development; the former symbolized by the sale of Red Ribbons, which Hollywood has turned into a chic global image of AIDS concern, the latter by the very large dances which a number of organizations have run, and which (as in the case of a couple of very big gay/lesbian parties sponsored by the New Zealand AIDS Foundation) become focal points for community recognition. For a number of organizations fund-raising is regarded as an integral part of the larger development strategy of the organization, involving mobilizing volunteers, developing community profile and increasing public awareness and support. In my experience, the area of fund-raising is also one of the most difficult for AIDS organizations, which not infrequently come to grief over the transition from small-scale local events to dealing with national events and major corporate donors. (In some places there has been an attempt to develop separate bodies with the sole mandate of AIDS fund-raising, the logic behind the creation of the AIDS Trust by the Australian Federation of AIDS Organizations.) Too often, fund-raising becomes an exercise in glamour, rather than resulting in either effective money raising or social education.

The Development of the People With AIDS Movement

The community-based AIDS movement represents a larger group than those who are infected with HIV, but increasingly the empowerment of those people who are positive is becoming central to community-based politics. Organizations among those who are themselves infected began independently in Africa and the United States, but have followed rather different itineraries. In both places some of the earliest community organizing involved People with AIDS (PWA), although many early US activists were not yet sick and did not know their status when they first

and solidarity, but American-style advocacy is true of stronger emphasis on political representation and advocacy than is true of groups found in Africa or other developing countries. As Richard Davenport-Hines wrote, drawing on British experience: 'The social identity of a person with Aids remains for the time being quite distinct from that of other terminally ill patients. It is more ruthlessly constructed by society at large: it is often and understandably reinforced by PWAs themselves; and it is further defined by the little specialised communities that try to support them: friends, lovers, volunteer and professional carers, and the histrionic ghouls who gather for the deathbed.'⁶⁵ (Note: in some countries other terms are used — People With HIV, or People Living With AIDS are both found, and PHA (People With HIV/AIDS) is replacing PWA as a generic term in North America. This discussion encompasses all of these variants, although there are certainly differences between the experience of being positive and healthy, and experiencing those illnesses which define one as having AIDS.)

The American model — which drew heavily on the gay legacy of 'coming out', in this case as positive — has become influential far beyond its borders which can lead to us overlooking the fact that there are other ways of reacting politically to a diagnosis which may be more culturally appropriate. Certainly in western liberal democracies, a belief in the importance of the individual asserting her/his rights was central to the rhetoric of emerging PWA groups, which argued for the centrality of positive people in any approach to the epidemic. The founding statement of the American PWA movement — the 1983 statement drawn up by a group of PWAs at a national AIDS Forum in Denver — stressed the importance of PWA involvement in a language which draws heavily on both the principles of gay and women's liberation and on ideas of patient empowerment.⁶⁶ In particular the Denver Principles stressed the use of the term 'PWA' as distinct from 'victims' or 'patients', and the need for representation at all levels of AIDS policy-making 'to share their own experiences and knowledge'.⁶⁷

'I believe that despair kills people with AIDS as much as any of AIDS's physical manifestations', wrote one of the founders of the PWA Coalition in New York. 'If we could truly believe in the possibility of living with AIDS, I think that survival figures would be higher.'⁶⁸ This mode of 'positive thinking' is a strong part of PWA rhetoric. At the presentation by the PWA group in Denver a banner was unfurled with what was to become the slogan of PWAs: 'FIGHTING FOR OUR LIVES'.⁶⁹ One of the authors of the Denver Principles, Michael Callen, was to have

In the United States, as in other Western countries, explicitly PWA groups were established after community-based organizations had come into being, and there has often been tension in defining their respective roles and relationships. The existing organizations — groups such as Gay Men's Health Crisis, Terrence Higgins Trust, the Australian AIDS Councils — are often viewed with suspicion by activist PWAs, who see them both as too ready to accept the agenda of the state and prone to ignore the real needs of PWAs. In turn I have heard workers in AIDS CBOs complain that those who claim to speak for PWAs often only represent a radical minority which disregards anyone positive who does not accept a 'politically correct' version of being a PWA.

These tensions play themselves out institutionally — for example in arguments about the need for open PWAs to be represented on all committees; in pressures to create affirmative hiring policies for PWAs; or in disputes over the allocation of resources between, say, treatments information and preventive education. They also play themselves out at a level of unacknowledged anger and guilt between those who are and are not infected. *Not* being infected can be as powerful a motivation for involvement in AIDS work as being infected, but it is likely to be accompanied with a sense of guilt *vis-à-vis* those who are, which makes a genuine dialogue difficult. It is very hard for those of us who are negative to resist the claims of activist PWAs to control the AIDS agenda, even where we may have disagreements with them, and this is exacerbated by the creation of a certain type of 'PWA identity', which is defined as constantly militant, proud and in the forefront of all AIDS-related struggles.

Discussing these issues in a major study of PWA identity and community, Robert Ariss — one of the founders of the PWA movement in New South Wales — tells a story of being interviewed by a gay journalist about 'how angry' he was. "'But I do not feel angry', I confessed with some embarrassment, a retort which doused his enthusiasm for seeking my considered opinion on this or any other issue for some time.⁷⁰ The PWA movement has produced a particular language, one which reflects the anger and urgency of those who are conscious of the rapidity with which their lives are being foreshortened. This is sometimes referred to as irrational, but it is rather an externalization of perfectly understandable feelings.

In some non-Western societies, less centered on the primacy of the individual, this identity and language may be less acceptable. At the 1991

Maxine Ankrah argued against centering the discourse on AIDS on infected individual rather than on her or his family, both biological and ascriptive.⁷¹ In an extension of this argument I have heard some African AIDS activists denounce passionately the call for people with the virus to 'come out', seeing this as divisive and counter-productive to the needs for total social response. Even in the context of western organizations there is often concern expressed — by PWAs as much as by others — that there is a risk of dividing those in the AIDS movement between negatives and positives, and forcing everyone who is not positive out of the struggle. When one prominent PWA called during a session at the 1992 Australian National Conference, for all those who were not positive to leave the room so as to create a 'PWA space' it was other positive people who were most angered.

I recognize the force of the argument against separatism, but it has to be balanced against evidence of successful PWA groups in a number of African countries, which provide the same sense of solidarity and mutual support evident in the West.⁷² Isolation, discrimination, need for knowledge of what services and treatments are available seem to be universal experiences of those infected: as one group in Pune, India, wrote: 'The Association for People with AIDS and HIV was created from the painful experiences of its office bearers... Each person had been harassed by organisations and doctors and this led to the growth of our organisation...⁷³ One should not underestimate the courage needed to declare oneself positive in a country such as India, where the prejudice and stigma associated with HIV is immense, and whose first openly positive person, Dominic D'Souza (now dead) was arrested by local authorities in Goa when he was diagnosed positive after voluntarily donating blood.⁷⁴ Dominic's arrest galvanized support from a number of quarters, and he was to go on to start organizing positive people in the country, but the attitudes he encountered are depressingly strong, extending right up to the top levels of the Indian government. And in many parts of the world those who are positive are, probably rightly, too frightened to declare themselves. As one AIDS worker commented ruefully after hearing of a young man in South Africa who was attacked with a spade by his brother when he declared his status, 'This isn't New York'.

Yet while it is enormously difficult for people who face all the issues associated with being HIV positive also to play an active role in confronting these attitudes, to do so can both empower them and help change social attitudes in very special ways. When three Filipino women went public on the occasion of World AIDS Day 1992, one observed

remained a 'them' issue but became personalised.⁷⁵ How powerful this 'coming out' can be was brought home to me at the very dramatic last plenary of the 1992 New Delhi Conference on AIDS in Asia and the Pacific, where all the speakers were themselves People with AIDS. For many of the doctors, bureaucrats and social workers from countries across Asia, this was the first time that they had seen PWAs as anything other than clients, and the presentations by the speakers had a very strong emotional impact on their audience.

In general, People with AIDS have tended to see themselves as having a role to play in the larger AIDS struggle, particularly as educators. As the American Richard Rector has written: 'In a world obsessed with power, let us never forget that we, people with HIV/AIDS worldwide, constitute a unique and critical resource... We are the ones living on the frontline and we can offer an expertise that cannot be learned elsewhere.'⁷⁶ (Elizabeth Reid puts it less rhetorically in her comment that the spread of the virus is affected by 'whether conditions exist for people to tell their stories of being infected, and their stories of changing their behavior to prevent themselves from being infected'.⁷⁷) The experience of those with the virus underlines the political and civil liberties dimension of the epidemic: in many societies to assert an identity based on HIV status is a subversive act. An early statement from the Brazilian group *Pela VIDA* (which stands for the 'Valorization, Integration and Dignity of the Diseased person with AIDS' [sic]) spoke of this:

This reality creates the need to discuss and open up spaces for the exercise and defense of the people who live with HIV/AIDS, specially the urgent social compromise to avoid the continuity of the situation. The strugglers unite and form civil organisations, calling society as a whole and the discriminated segments in particular for a comprehensive debate, in order to preserve individual freedom and to ensure every citizen's rights.⁷⁸

Of course PWA organizations function as much as self-help groups as they do as advocacy organizations, and for many their most important role is indeed the creation of space where PWAs can share experiences and find the comfort of not having to explain the realities of their situation because it is taken for granted. As one German PWA said of the drop-in *Cafe Positiv* in Berlin: 'Here I am myself. I can feel well or not well, but I am freer. In the *Cafe* it's normal to be sick.'⁷⁹

the AIDS Information Centre in Kampala, an organization primarily concerned with testing and counselling, can speak of 'the positive living concept' in terms which would be recognizable in PWA groups in San Francisco, Berlin or Toronto. Typical of the range of activities are those of the Sida Centre in Perth, Western Australia, which include information nights, communal meals, counselling, massage, art therapy, gardening, retreats and positive sex workshops: 'The centre is a social outlet, a place where people can form friendships and relationships on many levels, where tolerance, acceptance, understanding and reinforced self-worth are things people strive for and gain, secure in the knowledge that someone is there to offer empathy and the confidentiality which is so vital to the security of mind of those involved in the self-healing process, the process of learning to live with HIV.'⁸⁰ The PWA Coalition in New York for a while sponsored tea-dances so that positive gay men could meet others, and thus avoid the problems of seeking relationships in the larger gay world where rejection on the basis of one's positivity was perceived as a major issue.

Increasingly, AIDS organizations are working with growing numbers of openly positive clients, volunteers and workers, which creates new demands and tensions. Indeed, as will be discussed later, how far AIDS organizations are able to see the empowerment of those with the virus as central to their mission becomes a vital test of their ability to adjust to the changing nature of the epidemic.

Notes

- 1 Pollak, M. (1990) 'Policy in France', in Misztal, B. and Moss, D. (Eds), *Action on AIDS*, New York, Greenwood Press, p. 85.
- 2 Dan Bailey, quoted by Karloff, L. and Ince, S. (1991) 'Supporting People with AIDS', in McKenzie, N. (Ed.), *The AIDS Reader*, New York, Meridian, p. 552.
- 3 Letter from Don Shewey to author, August 25, 1993. There is a detailed discussion of GMHC buddies in Kuklin, S. (1989) *Fighting Back*, New York, Putnam's; and some observations in Adam Mars-Jones's story 'Slim' in Mars-Jones, A. (1992) *Monopolists of Loss*, London, Faber.
- 4 Figures are for 1991 (Lighthouse Fact sheets 1 and 2).
- 5 Davenport-Hines, R. (1993) 'A world apart', *New Statesman & Society*, May 21, p. 35 (a review of Cantacuzino, M. (1993) *Till Break of Day: Meeting the Challenge of HIV and AIDS at London Lighthouse*, London, Heinemann).
- 6 See Lapierre, D. (1991) *Beyond Love*, New York, Warner.
- 7 Aggleton, P., Weeks, J. and Taylor-Laybourn, A. (1993) 'Voluntary sector responses to HIV and AIDS: A Framework for Analysis', in Aggleton, P., Davies P. and Hart, G. (Eds), *AIDS: Facing the Second Decade*, London, Falmer Press.

- Journal of Community Health*, 19, 1, October/November.
- 9 See Barnett, T. and Blankie, P. (1992) *AIDS in Africa*, London, Belhaven, Chapter 7.
- 10 See Sergeant, J. (1992) 'Remarkable Women I have met... Women in Africa', *National AIDS Bulletin*, Canberra, November.
- 11 Mirken, B. (1992) 'The AIDS Revolution in Mexico', *PLAC Notes*, May/June, pp. 128-9.
- 12 Webb, L. (1993) 'Prevention, Care and Support', Seminar Proceedings: Beyond Compassion: Christian Responses to HIV/AIDS in Development Cooperation Activities HIV/AIDS and Development Program, Canberra, p. 45.
- 13 Willmore, B. (Ed.) (1990) Report of the Southern African NGOs Conference on AIDS: Workshop on 'Traditional Healers and the Role of Alternative Medicine', Harare, SANASO, pp. 51-2.
- 14 See sections on 'herbalism/traditional medicine' and 'witchcraft' in *Living with AIDS in the Community*, (1992) Ugandan Ministry of Health, TASO, UNICEF and WHO, Geneva, WHO.
- 15 From the back cover of 'The Act, *Action for AIDS*, Singapore, 6, 1993.
- 16 'WATCH's Activities and Progress', Kathmandu, Nepal, Mimeo, WATCH, January 1994.
- 17 'Presentation of AIDES Federation', mimeograph paper, Paris (nd).
- 18 For a discussion of the social marketing of condoms in Africa see Miller, S. (1993) 'How to sell safer sex', *New Scientist*, 27 February.
- 19 See Watney, S. (1990) 'Safer Sex as Community Practice', in Aggleton, P., Davies, P. and Hart, G. (Eds), *AIDS: Individual, Cultural and Policy Dimensions*, London, Falmer Press, p. 21. The pamphlet was published by *News From the Front*, New York, and was based on an earlier piece by Callen, M. and Berkowitz, R. (1982) 'We Know Who We Are', New York, Native, November 8, p. 29.
- 20 See Altman, D. (1986) *AIDS and the New Puritanism*, London, Pluto, p. 161.
- 21 *AIDSEED Newsletter* (1990) (Newsletter of the WHO/UNESCO AIDS Education and Health Promotion Materials Exchange Centre for Asia and the Pacific), Bangkok, p. 13.
- 22 'For Men Only' (1990) *World AIDS*, 12 November, p. 9.
- 23 See Allyn, E. (1991) *Trees in the Same Forest*, San Francisco and Bangkok, Ben Luang, pp. 263-4; Miller, N. (1992) *Out in the World*, New York, Random House, pp. 124-8. On EMPOWER see 'Empowering That women in their fight against AIDS' (1990) AIDS Health Promotion Exchange Global Program on AIDS, Geneva, WHO, 4, pp. 14-15.
- 25 See Campbell, C. (1991) 'Prostitution, AIDS and Preventive Health Behavior', *Social Science and Medicine*, 32, 12, especially p. 1375.
- 26 Kepp, M. (1990) 'Condom rule' protects Vila Minoza girls', *AIDS Watch*, 10, p. 6.
- 27 Coelho Reis, E. F. and van Buuren, N. G. (1992) 'Frustrated Alternative Actions', Poster presentation, VIII International AIDS Conference, Amsterdam.
- 28 Brown, D. (1992) 'Dark tide of AIDS in a sea of suffering', *Guardian Weekly*, August 23.
- 29 See Rowell, R. (1992) 'Enhancement of self-esteem: a basis for high risk behaviour prevention', *AIDS Health Promotion Exchange* (Amsterdam), 2, pp. 3-5.
- 30 Ong, W., Chan, R. and Kan, S. (1992) 'Outreach Programme for Gay and Bisexual Men in Singapore', Poster presentation, International AIDS Conference, Amsterdam, July.
- 31 See Talbot, D. (1990) 'Condom Condomum', *Mother Jones*, January, pp. 39-47.
- 33 *Bulletin*, June, p. 30.
- 33 Field, N. (1990) 'Picturing safer sex for lesbians', *Square Peg*, London, 29, p. 29. See also Schneider, B. (1992) 'Lesbian Politics and AIDS Work', in Plummer, K. (Ed.), *Modern Homosexualities*, London & New York, Routledge, pp. 160-74.
- 34 Sundaraman, S., Purushothaman, S. and Ganesh, A. K. (1992) 'Hapless victims', *Seminars*, New Delhi, 396, August, p. 32.
- 35 'Australia' (1991) (article on PRICS - Performers Releasing Information about Clean Syringes) AIDS Health Promotion Exchange (Geneva), 2, p. 8.
- 36 See Satriau, O. (1991) 'India wakes up to AIDS', *New Scientist*, November 2, pp. 19-23.
- 37 Frankenberg, G. (1992) 'Germany: The Uneasy Triumph of Pragmatism', in Kirp, D. and Bayer, R. *AIDS in the Industrialised Democracies*, New Brunswick, Rutgers University Press, pp. 106-7.
- 38 Friedman, S. et al. (1987) 'AIDS and self-organisation among Intravenous Drug Users', *International Journal of Addictions*, 22, 3, pp. 201-19.
- 39 Friedman, S., de Jong, W. and Wodak, A. (1993) 'Community development as a response to HIV among drug users', *AIDS*, 7(suppl. 1), S265-6.
- 40 Table 8.5 (1992) in Mann, J., Tarrantola, D. and Netter, T. *AIDS in the World*, Harvard University Press, p. 309.
- 41 See Seidel, G. (1990) 'Thank God I said no to AIDS: on the changing discourse of AIDS in Uganda', *Discourse and Society*, 1, 1, pp. 61-84.
- 42 Marvellous Mhloyi, (1993) 'Can a New Sex Culture Save the Next Generation?', *National AIDS Bulletin*, July, pp. 18-21.
- 43 Five Years of the STOP AIDS Campaign (1992) Basle, Swiss Campaign against AIDS, pp. 39, 15 (my translation).
- 44 See Bayer, R. (1989) *Pivotal Acts, Social Consequences*, New York, Free Press, p. 218.
- 45 'Censors Ban South African Safe Sex Video' (1993) *NAB*, August, p. 6.
- 46 See McKenzie, J. (1992) 'When You Say Yes', Melbourne, VAC/GMHHC.
- 47 See the discussion in Barnett, T. and Blankie, P. (1992) *AIDS in Africa*, London, Belhaven, pp. 156-7.
- 48 Lowry, C. and Connolly, M. (1992) 'Karate Kids Update', *NCHH AIDS Network Newsletter*, 15, January/February, p. 5.
- 49 Betchlyoun, W. (1993) 'AIDS magnifies existing conditions on a rural Indian reservation', *AIDSlink*, (NCHH Washington), March-May, p. 8.
- 50 Fortin, A. 'The politics of AIDS in Kenya' (1987) *Third World Quarterly*, 9, 3, September, p. 906-19.
- 51 Hill, P. and Murphy, G. (1992) 'Cultural identification in Aboriginal and Torres Strait Islander AIDS education', *Australian Journal of Public Health*, 16, 2, p. 156.
- 52 *EuroCASO*, Newsletter, 2, 91, April 1991, p. 3.
- 53 LILA, (1992) 'Civil AIDS', Milan.
- 54 See Lintner, B. (1992) 'Final solution' in Myanmar?, *WorldAIDS*, July, p. 4.
- 55 Mutembi, I. B. (1993) 'Institutional HIV/AIDS Policy and Human Rights', Presentation International AIDS Conference, Berlin.
- 56 For an example of this pattern see Farmer, P. (1992) 'New Disorder, Old Dilemmas: AIDS and Anthropology in Haiti', in Herdt, G. and Lindenbaum, S. (Eds), *The Time of AIDS*, London, Sage, p. 309.
- 57 See Somerville, M. and Orkin, A. (1989) 'Human rights, discrimination and AIDS', *AIDS*, 3(suppl. 1), S283.
- 58 Obituary for Colin Blakeney, Bay Area Reporter, June 17, 1993.
- 59 See Kayal, P. (1993) *Bearing Witness*, Boulder, Westview, pp. 186-8.
- 60 Kirp, D. and Bayer, R. (1993) 'Needles and race', *The Atlantic*, July, p. 39.

- Yale University Press, pp. 117-26.
- 62 Unidentified speaker in proceedings of Workshop (1991) on 'AIDS, NGOs and Private Sector Initiatives', National Council for International Health, Crystal City, Virginia, June 27.
- 63 Tero, V. (1992) 'Solidarity is a big enterprise!', *AIDS Action*, September, 18, p. 3.
- 64 See Zwi, A. and Bachmayer, D. (1990) 'HIV and AIDS in South Africa: what is an appropriate public health response?', *Health Policy & Planning*, 5, 4, especially pp. 323-4.
- 65 Davenport-Hines, R. (note 5).
- 66 I am indebted to Robert Ariss for some of this discussion. See Ariss, R. (1992) 'Against Death: The Sydney Gay Community Responds to AIDS', unpublished PhD thesis, University of Sydney, Chapter 9.
- 67 The 'Denver Principles' are republished in Calten, M. (1988) *Surviving and Thriving with AIDS: Collected Wisdom*, Vol. II, New York, PWA Coalition, pp. 294-5.
- 68 Navarre, M. (1988) 'Fighting the Victim Label', in Crimp, D. (Ed.), *Cultural Analysis, Cultural Action*, Cambridge, Ma, MIT Press, p. 144.
- 69 See Nussbaum, B. (1990) *Good Intentions*, New York, Atlantic Monthly Press, pp. 107-10.
- 70 see Ariss, R. (1993) 'Performing Anger: Emotion in Strategic Responses to AIDS', *Australian Journal of Anthropology*, 4, 1, p. 18-30.
- 71 See Nowak, R. (1991) 'Preserving the Family', *Science vs. AIDS* (Bulletin of the 7th International Conference on AIDS), June 19, p. 3.
- 72 See, for example, the discussion of Rwanda in the interview with Donald de Gagne (1993) *Global AIDS News*, 1, pp. 22-4.
- 73 Pamphlet from Association for People with AIDS & HIV Infection, Pune (nd, probably 1992).
- 74 See D'Souza, D. (1993) 'State and societal reaction towards people living with HIV/AIDS in India', *National AIDS Bulletin*, February, pp. 12-14.
- 75 Bagasso, T. (1993) 'Filipino Women and AIDS', *National AIDS Bulletin*, February, p. 17.
- 76 Rector, R. (1991) 'Maximising the existing health potential of people with HIV/AIDS', *AIDS Health Promotion Exchange WHO*, Geneva, 1, p. 4.
- 77 Reid, E. (1992) 'The Global Spread of AIDS', *National AIDS Bulletin*, August, p. 30.
- 78 Grupo Pela Vidda, 'Promoting Civil Rights to PWAs', undated flyer (in English).
- 79 Passarge, I. (1992) 'Ich will mehr nicht verstecken' *Magnus Deutsche AIDS Hilfe*, Berlin, p. 21.
- 80 Rank, F., Marshall, R. and Parlavocchio, R. (1992) 'The Emergence of an HIV/AIDS Community in WA', *National AIDS Bulletin*, October, p. 15.

Chapter 4

The Changing Pandemic

Epidemics are not static, and in the short history of the AIDS epidemic there have been rapid changes to the conditions affecting the community response. Shifts both in the epidemiology of the epidemic and in possibilities for treatment have had a major impact on the nature of the community response. In 10 years AIDS has developed its own economy with hundreds of millions of dollars involved in pharmaceutical research hospital wards, foreign aid, and international conferences. In the United States, doctors specializing in HIV advertise with billboards on West Hollywood streets, and take out full page color advertisements in gay magazines. Growing numbers of professionals depend on the epidemic for their careers, and international consultancies further benefit those from the rich world in the name of helping the poor.

In most Western countries, as we have seen, the initial CBOs grew out of gay communities, and reflected the early epidemiology of the disease. The first concern of the early groups was to obtain information about the mysterious new illness which seemed to be sweeping the communities: this led to pressure and support for research, for preventive education, for provision of general information (e.g. through hot line public information meetings etc.). Fairly quickly, programs were developed which involved care for those who were sick, usually as some variant of the 'buddy' or as direct services to patients. In some ways the two broad areas — education and care — have remained the basic focus of CBO work ever since. Yet, the meanings of 'care' and 'education' have changed considerably.

An excellent example of how this has occurred comes from the development of largely reliable tests for HIV infection. Before the virus was identified and named in early 1985 testing was of course impossible

AIDS organizations about whether or not to advocate its use.

Most people in the community sector initially viewed the test with great suspicion. (One early advertisement of GMHC in New York warned that: 'The test can be almost as devastating as the disease. ¹) It was feared that to test positive would put individuals at risk of considerable discrimination, without any countervailing benefits existing in the way of available treatments. Some people argued that testing and counselling was an important element of AIDS education policies; others replied that the only safe prevention policy was one where it was assumed that all potential sex (or needle) partners might be positive. In the absence of any effective medical intervention for those who tested positive it was argued that the psychological consequences of knowing one was positive might outweigh any benefit, a position which seemed to be borne out with occasional reports of suicide by people who had learnt of their positive status. Complex issues emerged around the question of testing pregnant women, where knowledge of one's positive status might lead to a decision to terminate pregnancy.²

This debate soon overlapped with arguments about who should determine AIDS policy. In general, testing was most strongly argued for by traditional public health officials, who saw it as a means of effecting control over the progress of the epidemic (and of those infected). Groups representing affected communities were usually far more sceptical, and jurisdictions where they had a major impact on public policy (e.g. The Netherlands) de-emphasized testing, preferring to stress the need for widespread educational strategies. Not surprisingly where traditional medical authorities are dominant, such as the former Soviet Union, many more resources remain likely to be placed into testing than into education programs. Some medical authorities still advocate mass testing, even where it is not clear who would benefit from the results. The available evidence suggests that various programs of compulsory testing — whether of 'high risk groups', of pregnant women, of hospital and STD clinic patients or, as in some US states, of applicants for marriage licences — are likely to be counter-productive.³ Moreover, there are the crucial issues of resources: mass testing — especially if accompanied by any form of counselling — is expensive, and uses resources which might be more sensibly devoted to prevention and care.

The nature of the testing debate began to change as medical advances started to suggest that early intervention might be possible, and, indeed, that if one took drugs such as azidothymidine (AZT) as soon as one became positive this could slow down the progress of disease. As early as

gay men should get tested and, if positive, immediately go onto AZT. At this time, most Australian AIDS organizations were at best lukewarm about testing, none so more than my own, the Victorian AIDS Council. Over the next few years, however, attitudes changed quickly, as evidence of the efficacy of early intervention mounted, and AIDS organizations came to promote testing as a central policy. In countries with access to medical technology concern for discrimination came to be overridden by faith in the ability of early treatments. Elsewhere the situation remains, as Parker and Daniel wrote of Brazil:

Virtually no free, anonymous testing sites are available or equipped with adequate psychological counselling services, and individuals involved in practices or behaviors that place them at risk must thus choose between living with the uncertainty of remaining untested and what they may well perceive to be the even greater risk of being tested under circumstances that may protect neither their confidentiality nor their basic human rights.⁴

This is largely true of most of the developing world; one of the great achievements of TASSO was to establish the AIDS Information Centre, the first site for anonymous testing and counselling in sub-Saharan Africa.

There is a further theme in the testing debate, which is scepticism about the central role of HIV as a cause of AIDS. While this argument has been largely confined to the United States — where the anti-HIV position is associated both with Berkeley scientist Peter Duesberg and the gay newspaper *The New York Native*⁵ — echoes of it occasionally are heard in other countries. Thus at the 1991 International Conference for People with HIV and AIDS, one speaker, Haydec Emilia Pelligrini from Uruguay, argued: 'Is Duesberg not correct when he argues that AIDS is the result of an ecological imbalance and not the product of an infectious agent? Should we not pay attention to the fact that... the most polluted and the hungriest nations have suffered harshest the initial impact of the disease.⁶ While I am sympathetic to the analysis of the *impact* of the epidemic made by Pelligrini, the evidence for HIV as the primary cause of AIDS seems to me overwhelming. More significantly, there are few examples of the community-based movement resisting the HIV hypothesis, as shown by widespread acceptance of the term 'HIV/AIDS'.

At the time of writing, AIDS organizations are beginning to come to terms with the even more complex issues posed by vaccine development. As vaccines have both therapeutic and preventive possibilities — and as

concerns are unlikely to be easily resolved. There is considerable concern among a number of community groups about the nature of vaccine trials commonly underway in both rich and developing countries; as the Brazilian group *Pela-VÍDDA* São Paulo has stressed, the ethical questions need to be considered within the framework of discrimination, the class-based power of medical authority and the 'increasing pauperization of the epidemic'.⁷ Australian community organizations are involved in a number of consultations with researchers about vaccine development, and there are some fears that the medical and pharmaceutical authorities will take note of such consultations only to the extent necessary to recruit subjects for their trials.

It is the possibility of treatment advances which has been the dominant factor in the radicalization of the AIDS movement in industrialized countries, and the issue is inextricably bound up with the emergence of AIDS activism and groups such as ACT UP. This in turn has been closely connected to the energies and anger of people infected with HIV: in most Western countries by the late 1980s, PWAs were demanding and taking leadership of the community sector, sometimes bypassing existing organizations to establish their own. Not surprisingly, PWA activists, who quickly became experts in the medical literature, began pressure for expanded drug trials and the involvement of general practitioners and community groups in trialing new therapies. The Community Research Initiative (CRI) in New York City emerged from an alliance of disgruntled doctors and PWAs, and has played a crucial part in the fast-track testing and approval of new drugs. The first grassroots community trial took place in New York in 1984, largely due to the efforts of three people: Dr Joseph Sonnabend, whose Manhattan practice had brought him large numbers of early AIDS cases; Mathilde Krim, a cancer researcher and founder of the American Foundation for AIDS Research (AMFAR); and Michael Callen, one of the founders of New York's PWA group.⁸ This involved the drug isoprinosine, but the most remarkable success of the movement were the tests which showed the efficacy of aerosol pentamidine as a prophylaxis against PCP (*pneumocystis carinii* pneumonia). Tests began in New York and San Francisco in 1986, and by 1989 the results had persuaded the Food and Drug Administration (FDA) to accept the commercial sale of the drug for the prevention and treatment of PCP — 'the first time ever that a drug had been approved based on grass-roots research.'⁹ Its defenders could claim that CRI has proved that a community model of research, involving PWAs themselves in decision making, could run effective trials — partly because it was able to

and could resolve the complex ethical questions of such research successfully.¹⁰

Closely related to these efforts was the development of a number of organizations, such as Project Inform in San Francisco (started by Martin Delaney in 1985), which seek to provide the latest information about drug advances and to help organize 'buyers' clubs' that get hold of new treatments and drugs (often across national boundaries) not yet officially approved. Similar information in Britain is provided via the National AIDS Manual. Through direct action, involvement in drug trials, the spreading of detailed therapy information, and the provision of banned or expensive drugs through what is sometimes called the guerrilla underground, People with AIDS asserted a role for themselves in the management of their condition that has no real parallels in medical history.¹¹

More than anything else, it was a feeling that research on treatments was not being properly funded and was being delayed by bureaucratic red tape that led to the foundation of ACT UP (AIDS Coalition To Unleash Power) in New York in 1987, 'a diverse nonpartisan group united in anger and committed to direct action to end the AIDS crisis'.¹² (The need to speed up treatment research was the major theme of Larry Kramer's speech at the Gay and Lesbian Community Centre in March 1987 which was the inspiration for the birth of ACT UP.)¹³ ACT UP attracted activists who were propelled by intense anger and were able to channel this anger into very effective forms of protest, which captured the attention of the media and dramatized the issues they made their own, largely the process of drug approvals, access to drug trials and the costs of treatments.

The base for ACT UP was the very large number of predominantly gay men in New York and other American cities who were themselves either positive or close to those who were. For them, ACT UP was a cathartic experience, a way of channelling rage, anger and fear into collectivist political expression against 'an enemy' who could be personalized — in the shape of the President, the Food and Drug Administration, the drug companies — more convincingly than could a virus. It is not meant to demean in any way the extraordinary political savvy of ACT UP — nor its achievements on the drug front — to point out that for many of its followers it was as much about acting out as acting up. This is borne out by a comment of Joshua Gamson in his very perceptive — and largely sympathetic — account of ACT UP: 'They were, in effect, their own audience, performing for themselves and making others perform for them.'¹⁴ Gamson corroborates the view of ACT UP as

...youngly in a footnote — the significant numbers of women involved in AIDS activism, though not distinguishing how many of them identify as lesbian.¹⁵ ACT UP is clearly one of the organizational forums where a feminist analysis of AIDS has been able to have some impact, and considerable tension has at times arisen between this analysis and the desire of gay men to stress their epidemiological pre-eminence. In San Francisco, at least, this led to a major split, and for a short time there were two ACT UP organizations in that city.

Those achievements are considerable and have had a lasting impact on the ways in which new therapies have become available to patients. While ACT UP acted as a ginger group in pressuring the drug approval agencies, it also provided people who became themselves experts in the issues, able to engage in direct participation in the very complex processes by which new treatments become available. As one of the best known spokespersons for ACT UP, Mark Harrington, put it: 'None of [our] efforts would have been effective had not AIDS activists learned the jargon of the medical establishment and turned it towards their own aims.'¹⁶ Pressure from treatment activists have had a major impact on the ways in which drug trials are conducted, on expanding them to include women, drug users, and people of color (often excluded for the traditional reasons which see an over-representation of middle class white men in most drug trials), and on challenging the right of pharmaceutical companies to set whatever price they like for their products. The reorganization of US research efforts through legislation, which established the Office of AIDS Research in the National Institutes of Health in 1993, owed a great deal to pressure from the Treatment Action Group of ACT UP and the AIDS Action Council.¹⁷ Drug companies, too, responded to the challenge of the new style activists, in particular Burroughs-Wellcome, manufacturer of AZT, and the focus of much early protest by ACT UP such as the invasion of the floor of the New York Stock Exchange in September 1989.¹⁸ In the 1990s, the company had developed Community Advisory Boards in a number of key cities, and was frequently advertising its sponsorship of 'community forums' etc. It is difficult not to be cynical about the appearance of ACT UP personnel in advertisements paid for by Burroughs Wellcome promoting the advantages of testing and early medical intervention, especially when these are read in conjunction with leaflets of several years earlier calling for boycotts of Burroughs-Wellcome products.

Although debate about the value of using AZT has been loudest in the US, it reached its most bitter point in London in 1993 when two

after breaking an injunction against their picket of the Terrence Higgins Trust, which they accused of 'murder' through its advocacy of the use of AZT.¹⁹ Although their claims went far beyond the views of all but the most extreme medical sceptics, the incident was a painful reminder to AIDS organizations of the responsibilities involved in urging people to seek early treatments which may prove less effective than originally thought.

It would be silly to declare that every activist claim for treatment access has been successful; the short history of AIDS contains many accounts of people breaking restrictions on access to treatments which have proved no more than expensive and sometimes fatal quackery. (There are obvious parallels in the history of cancer.) Many of us know people who have defied official regulations to travel overseas in search of elusive cures, whether it be massive vitamin inoculations in the Bahamas or ozone therapy in the Philippines. How far the state is justified in regulating access to treatments for those who can hope for no cure from officially sanctioned therapies is one of the major ethical issues thrown up by the epidemic, and at the time of writing this is brought into sharp relief by the general gloom which currently pervades the treatment news. Thus, in September 1993 activists reversed a previous stand to call for withdrawal of approval for the drug zalcitabine (ddC). 'We have arrived in hell', said Gregg Gonsalves of the Treatment Action Group. 'AIDS activists and government regulators have worked together, with the best intentions, over the years to speed access to drugs. What we have done, however, is to unleash drugs with well documented toxicities onto the market, without obtaining rigorous data on their clinical efficacy.'²⁰

The American treatment activists quickly became an inspiration for groups overseas. In Canada, a public meeting in Toronto during late 1987 saw the establishment of AIDS Action Now! This group took up Canadian concerns surrounding drug testing and treatments, and set out to embarrass the federal government for its slowness to respond to the epidemic.²¹ (One study of the Canadian response describes a protest organized by AIDS Action Now! at the 1988 National Conference on AIDS as sending 'shock waves through the corridors of power in Ottawa.'²²) Changes to the Australian drug approvals system — one of the most cumbersome and slowest in the Western world — were largely due to the pressures of PWAs and AIDS organizations inspired and informed by the American model.²³ And while such activism has been almost entirely confined to the developed world, initial links have been established with groups in developing countries, sometimes enabling drugs to be sent to those in need as AZT has been sent from Australia to

is unlikely that the World Health Organization would have involved community groups in discussions about the protocols for HIV vaccines, which, particularly in developing countries, is very unusual in medical research.

Not everyone involved in ACT UP is gay, and yet it is clear that ACT UP is essentially a product of the gay movement even where, as in some of its chapters, it has tried to emphasize the inequalities in American health care based on race and gender.²⁴ (Some commentators have identified ACT UP as 'a gay organization'.²⁵ Others have been more inclined to stress the high percentage of seropositive members, although in both cases these descriptions are not fully inclusive.) The dramatic protests of ACT UP, and its ability to instigate effective acts of civil disobedience, are very reminiscent of the early actions of gay liberation. (Interestingly, one commentator even uses the term 'zaps' in speaking of ACT UP, a term associated with early 1970s gay activism.²⁶) The slogan 'SILENCE = DEATH' has become a global symbol of ACT UP's anger and flair for public relations. I might note that I have some reservations about this slogan, and the tendency in some ACT UP rhetoric to equate negligence with 'murder', a tendency which Richard Mohr identifies as a confusion between acts of omission and acts of commission.²⁷

More clearly ACT UP is American, and its attempts to promote itself as an international movement have often antagonized others even though there are now ACT UP chapters in at least six countries outside the United States, with that in Paris probably the best established. One of my favorite encounters of the last decade was with an American who had gone to Montreal after the International Conference in that city in 1989 to found a local ACT UP chapter. When I asked him whether his lack of knowledge of French might not be a problem he brushed the question away as irrelevant, although language divisions have dogged community organizing in Quebec as they have almost everything else. The 'ugly American' is unfortunately not only found on the right. Equally, Americans have been prominent in the establishment of most European ACT UPs: it is revealing that a German book on ACT UP, with the wonderful title of *Fire Under the Arse*, and identifying chapters in nine German cities, consisted almost entirely of pieces by Americans.²⁸ (There are, of course, some forms of AIDS activism which have developed independent of ACT UP. In India, for example, the group ABVA, a loose grouping of activists in Delhi which grew out of the local human rights movement, have been a vocal force attacking AIDS-related discrimination and neglect.)

BY SUCH FORCE OF... in American AIDS politics (and, by extension, internationally). Beginning in Montreal, ACT UP has been a major presence at international conferences, and considerable attention has been given to placating it.²⁹ This in turn has alienated many, including other activists, who feel that stand-over tactics are no more appropriate when used by ACT UP than anyone else. (One New Zealand observer of the 1993 Berlin International Conference complained of 'the embarrassing form of ACT UP whinging'.³⁰) ACT UP's strength in the United States was strongly related to the sense of alienation from government brought about by 12 years of Republican Administrations; it is perhaps not an accident that in 1993, as the Clinton Administration took over, ACT UP seemed to be on the decline, with several local chapters going out of existence³¹ and questions being asked in others about the relevance of its approach.

The growing emphasis on treatment issues matches the growing importance of PWAs within AIDS organizations and a corresponding decline in emphasis on the needs for education and outreach to those who are not infected. (The two approaches can of course be bridged by an education program which accepts the importance of targeting those who are positive in seeking to prevent the spread of the virus.) Some PWAs have insisted that they must be accepted as leaders in all AIDS organizations; as the German activist academic Udo Schuklenk put it: 'Democratic control means control of "community based" organizations by people with AIDS, and not, as usually nowadays by perfectly healthy gay guys or other non-affected interest groups.'³² This is an unsettling demand for those negative gay men who see themselves as central figures in the emergence and development of the AIDS movement.

New Constituencies, New Issues

The shape of the epidemic has changed since the mid-1980s, and with it the possibilities and constraints for community response. In some — not all — Western countries it has moved from being overwhelmingly concentrated among homosexual men and men with hemophilia, spreading, via needles and heterosexual sex, to a broader population. (Of defined populations none have probably been as badly hit as people with hemophilia, almost half of whom in at least five countries — Brazil, Canada, France, Spain and the United States — were estimated to be seropositive by the end of 1990.³³) In a few areas of the United States, almost all in the inner cities of the east coast, AIDS is now a disease largely

cases of HIV seemed far more heavily concentrated amongst black and hispanic than other Americans. In developing countries, early complacency that HIV would be restricted to prostitutes and foreigners remains a plausible delusion in a declining number of countries.

In the United States, where these changes seemed most dramatic, it was argued that this would inevitably lead to a decline in the gay stake in the epidemic. As a result of the decline in percentage of new cases due to homosexual transmission, Robert Padgug and Gerard Oppenheimer have argued that the gay-based AIDS organizations, 'although jealous of the immense effort and money it took them to achieve their current position... will inevitably have to share it with newer, non-gay groups'.³⁴ (There is striking evidence of the extent to which gay men sometimes find it hard to 'share' AIDS in gay sociologist Philip Kayal's observation in his study of GMHC that: 'Homophobia is the most important social dimension of AIDS'.³⁵ To write this of New York City in 1993 seems to me to verge on precisely the sort of blinkered gay chauvinism which many established AIDS organizations find themselves wanting to deny.)

Certainly there has been a rise of organizations based in communities of color, and sometimes tensions between them and the older established agencies are palpable.³⁶ (In 1993 a bitter dispute over city funding for HIV broke out in Washington DC, in which mutual accusations of discrimination were made by black and gay leaders, and the director of the City's Agency for HIV/AIDS was fired after allegations of pro-gay bias in the allocation of contracts.³⁷) While there are alliances between black, hispanic, Asian American and Native American groups — which at a federal level work through the National Minority AIDS Council (NMAC) — there are also tensions at times between minority groups, and the same suspicion and jockeying for resources as new groups become more directly affected. Early in the epidemic there was considerable discussion in San Francisco at street level of why so few Asian-American men were apparently untouched; by 1993 the National Asian/Pacific Islanders HIV/AIDS Leadership Forum could point to CDC figures as showing that 'Asians and Pacific Islanders currently have the greatest increase of new cases of AIDS of all racial/ethnic groups'³⁸ and special programs aimed at various Asian communities were being established. Among 'minority populations' there are special problems for women, who tend to be even more marginalized and lack the visibility black men have achieved through such high profile PWAs as Arthur Ashe and Magic Johnson.³⁹ But there are also special problems for homosexual black, hispanic and other non-Caucasian men, who often feel a lack of support from both the

mainstream black society.⁴⁰ Some mainstream gay agencies have committed themselves to major attempts to break down racial and ethnic lines among homosexual men, as in the San Francisco AIDS Foundation 'gay/bisexual men of all colors program'.

It is easy to point to the problem, less clear to find easy solutions. When organizations do seek to make major changes to accommodate the new profile of the epidemic they risk alienating their original constituency (and funders). When I visited AIDS Project Los Angeles in mid-1993 a number of staff were very concerned at what they saw as a deliberate de-gaying of the agency, symbolized by an attempt to restrict the display of explicitly gay material on office walls. The racial bitterness of Los Angeles, the growing financial crisis in the state of California, and the gulf between the experience of middle class gay men, predominantly living on the west side of the city, and that of Latinos living in East Los Angeles makes any attempt by the agency to satisfy all its possible constituents very difficult. While some of APLA's programs clearly reach out across the city — the Project operates a very successful Food Bank whose clientele is drawn from all areas of Los Angeles County — it continues to depend upon the leadership and resources of white gay men, which in turn promotes considerable resentment from other agencies. The sort of balance required is summed up in the phrase used by GMHC: it identifies itself as 'committed to the practice and realization of multiculturalism and with a special commitment to the lesbian and gay communities'.

It has become a cliché to observe that AIDS organizations need to integrate new communities into their work as the shape of the epidemic changes, and to ensure they get adequate access to already stretched resources. Most countries today are increasingly multi-ethnic and multi-lingual — this is as true in Sweden, Canada and Germany as in India or Nigeria — and the need for culturally and linguistically sensitive AIDS education materials reoccurs in discussion of HIV/AIDS programs from almost everywhere. Sometimes this overlaps with larger questions about the balance between direct services for people with HIV and prevention programs, as class and ethnic differences open up between those perceived most at risk as against those already positive.

Even in those countries — in Scandinavia, The Netherlands, Australasia, and most of Canada — where HIV remains heavily concentrated among homosexual men, tensions constantly surface between an AIDS-specific and a more general 'gay' agenda. Writing of Denmark, Erik Alback has identified the way that the (smaller) hemophilic community was able to skillfully use the political system to

winning from the state a right to monetary compensation accorded no other group affected by the virus:

No other risk group was able to define its risk of infection as a public responsibility. By privatizing sexual conduct, the gay community removed the possibility of claiming public responsibility for their infection, and even made it possible to distinguish 'blameless' victims from those 'responsible' for HIV infection through their own private acts. The leadership of the gay and the medical communities opposed giving economic compensation to hemophiliacs. Once again the DHS [Danish Hemophilia Society] was exceptionally skillful... the DHS was able to press its concerns in a political climate in which the hegemony of the medical profession over health policy was increasingly being questioned.⁴¹

Similar tensions between hemophilic and gay-based groups are found elsewhere; the Hemophilia Foundation of Australia has refused overtures to join the Australian Federation of AIDS Organizations (AFAO), largely because they can probably do better by directly negotiating with the government but also, undoubtedly, because of distaste at too close a link with what are perceived to be essentially gay organizations. In Germany, Guenter Frankenberg has noted that Deutsche AIDS Hilfe has made a particular effort to reach drug users, prisoners, and sex workers — which has sometimes been met by criticism that 'the gay-dominated AIDS-Hilfen have effectively colonized junkies, prostitutes and prisoners, speaking for them instead of enabling them to be their own advocates'.⁴²

As the epidemic moved from being an immediate crisis to a long term condition, affecting greater and more varied numbers of people, it would not have been surprising to see a drastic drop in the significance and numbers of volunteers involved in AIDS work. Perhaps surprisingly, most major agencies in developed countries seem still able to recruit a steady stream of new volunteers, as more and more people come into contact with the impact of the epidemic. In 1993, AIDS Project Los Angeles (APLA) could claim almost 2000 volunteers, a figure which is matched (considering relative populations and levels of illness) by groups in many other cities and countries. 'It is the volunteers who have been the heart of the agency', proclaimed APLA, claiming that its volunteers by the end of 1991 had contributed over 800 000 hours (i.e. over ninety person years) to persons with AIDS.⁴³ Whether the supply of volunteers can meet the

moving into communities of color, with different needs, resources and cultural patterns to the earlier epidemic, is not clear. Yet already there are many examples which suggest that direct work with People with AIDS brings together people who one might assume have nothing in common, as in the frequent cases of young gay men working with Latino families, or conventional middle class women providing home care to men heavily involved in the gay ghetto.

That so many of the volunteers in community-based organizations are not themselves part of the core communities affected by HIV has been seen by some observers as replicating already existing inequalities. Cindy Patton has noted that: 'The media valorized the gay male volunteer who put aside careers and personal fears of AIDS to care for his brothers. Heterosexual white women also volunteered in large numbers, but not because they were depicted as at risk of HIV from their boyfriends or husbands, but because they are the traditional volunteer reservoir. Many women were personally affected by gay male friends with AIDS, but they were not encouraged to understand this experience in the social context of their participation in gay male culture.'⁴⁴ What Patton sees as a problem of sexism is seen by some as a problem of ownership, and some gay commentators see the growing number of female volunteers as diluting the necessary community base and community building mandate of the AIDS movement.⁴⁵

The above examples speak of volunteers in the most traditional sense, usually involved in direct care of those with AIDS; when we speak of the other functions of AIDS organizations — education, fund-raising, lobbying, policy formation — the large groups in most western cities remain heavily dominated by white, middle class gay men. In Sydney or Stockholm this continues to make sense; it is more problematic in places, such as Milan or Miami, where there is a significant number of people from other backgrounds, either heterosexual drug users or people of color. The strength of the community-based organizations has lain in the links between those affected and those working with them; it is not clear that the same sort of links, and thus the model offered by the existing organizations, is appropriate for different populations whom the epidemic is increasingly affecting.

One of the most dramatic ways in which the changing shape of the epidemic impinges on the community sector is the burden of sickness, death, loss and grief on the organizations themselves. Many of the people who founded the earliest organizations, whether they be American gay men or African women, are themselves now dead, and the load this places

after I attended the funeral of a former worker for the Victorian AIDS Council. At the subsequent wake the leader of his care team said he had buried three men in the last eighteen months, and it was time for a break.) The sheer dimensions of loss in those communities most affected — in Uganda and New York, in Rwanda and Paris — makes it difficult for organizations to continue. AIDS organizations may be becoming more permanent, more professionalized, 'in this for the long haul' as is sometimes said, but they grow out of and serve a population which is fragile and in a state of constant crisis as more and more of its members fall sick and die.

Within particular and already stigmatized communities this will have very special consequences, which in turn impinge upon the ability of the community to respond. In his frustratingly opaque piece, 'Mourning and Melancholia', Freud wrote: 'Now the melancholic displays something else which is lacking in grief — an extraordinary fall in his self-esteem, an impoverishment of his ego on a grand scale... The distinguishing mental features of melancholia are a profoundly painful dejection, cessation of interest in the outside world, loss of the capacity to love, inhibition of all activity, and a lowering of the self-regarding feelings to a degree that finds utterance in self-reproaches and self-revilings, and culminates in a delusional expectation of punishment.'⁴⁶ This 'fall in self-esteem' may be linked with grief in many communities hit by AIDS, whether this be the gay communities of the Western urban world or the villages of Central Africa. Certainly some of the American literature on grief and loss in the gay community suggests widespread feelings of abandonment, depression, apathy and anger which echo Freud's words, sometimes linked to withdrawal from both the community and even from personal and sexual relations.⁴⁷ A feeling that 'we're all going to die', as one of the characters expresses it in Andrew Holleran's very powerful story 'Friends at Evening',⁴⁸ haunts some of the most affected communities, and makes rational responses difficult. Similar reactions are reported from Africa:

A report carried out in five villages in Rakai [Uganda]... found evidence of depression being experienced on a massive scale. It manifests itself in poor communication within families, between individuals, and between community leaders and members. There is a lack of cohesion in the community, and traditional groupings for mutual help and support, such as the extended family system, are collapsing. Juvenile delinquency among unemployed youth is on the increase. In addition to the depression caused by

accusations and counter accusations among the men, women and younger people as to who is mainly responsible for spreading the disease.⁴⁹

What this means for people is spelt out in this report by Elizabeth Reid:

The most striking feature... is the psychological impact on individuals and communities of so many lives lost, so many parents, siblings, friends, children, colleagues, neighbours dead. In young children this often induces an almost catatonic state, a withdrawal from the world of pain and despair. One story from the Kagera region in Tanzania is of a young girl sitting day after day at the edge of the yard, rocking on her heels and staring into space. Both her parents are dead, brothers and sisters, aunts and uncles. There is little food but she is not hungry. She rocks, grieving.⁵⁰

If AIDS is seen as a curse or a punishment, as much religious discourse suggests, its impact will strengthen deep and irrational feelings of personal inadequacy, and this in turn will influence communal responses. One of the most common aspects of AIDS politics — an anger directed at those also working in the area — is closely linked to the mechanisms which Freud describes in 'Mourning and Melancholia'.

The Cultural Response

The short history of the epidemic is marked by a distinctive cultural response, itself often shaped by community organizations such as the Names Project which manages the AIDS Quilt. A whole book could be written on cultural responses to the epidemic, ranging from such elaborated forms of community memorials as the Quilt and Candlelight Vigils, to small scale village ceremonies for the dead. Such responses are clearly very dependent on existing cultural norms, and it is not surprising that they tend to be particularly associated with Western gay communities, which had significant pre-existing links to mainstream cultural institutions. Yet it is interesting that the greatest impact of all the cultural responses to the epidemic has almost certainly been the Quilt, which grew out of American popular tradition and was developed into a powerful

States.

The Names Project began in San Francisco in 1987, after gay activist Cleve Jones had been inspired some time earlier by placards memorializing those dead from AIDS during a candlelight march. Drawing on the American tradition of making quilts to mark special occasions it has become a major communal tribute to those who have died from the epidemic, and literally tens of thousands of panels have been woven, each of them a personal tribute to a particular loss.⁵¹ The full Quilt has been unveiled in several major ceremonies in Washington, but panels are constantly on display across the country and now — as the Quilt has been adopted as an AIDS memorial in many other countries — across the world. At the first major showing of the Quilt at the October 1987 lesbian and gay march on Washington, Cindy Patton noted the contrast with the Vietnam Memorial Wall: 'No one could help comparing the brightly coloured quilt, which covered an area greater than two football fields, with the sombre grey granite of the Wall... Many of the lesbians and gay men who came to the March visited the Wall, where one heard gay men talking about being in Vietnam and compared losing friends there to losing friends to AIDS.'⁵² The growth of the epidemic has been matched by the growth of the Quilt: from two football fields in 1987 to twelve (roughly 13 acres), embracing 20 000 panels, when it was displayed again in Washington in late 1992.

Yet if the Quilt grew out of the gay community, it has become a meaningful way of expressing loss to people of all sorts, and its images show the changing patterns of AIDS in America. The public expression of grief around AIDS takes on a deeply political purpose. Such collective undertakings will have many meanings, as Marita Sturken has identified:

For many AIDS activists, mourning is transformed into action through collectivity. AIDS activist Douglas Crimp writes: 'For many of us, mourning becomes militancy.' However for others, mourning in the face of AIDS takes different forms: for those in inner-city communities, mourning in the face of AIDS may be more often tinged with the rage of despair rather than the anger of a middle class sense of entitlement. For many families, mourning is a processing of feelings of shame and guilt. Mourning is defined by the Quilt as a cathartic and healing process, one that is ongoing and diminishing in intensity, both angry and hopeful.⁵³

While the concept of the Quilt grew out of a specific American tradition, it

Quilt projects in over twenty countries, including Brazil, Israel, Thailand, and Zimbabwe. Its universality is captured by Peter Blazey's observation that: 'What makes it moving are the evidences of that person's life — comic, personal, loving — that are presented before your eyes, helping recall if you knew him or her; or summoning the person up if you didn't. This is not a unilateral act. It is a mutual act, like an act of love, requiring give and take on both sides.'⁵⁴

Equally, the Candlelight Vigil for those dead from AIDS has spread far from its origins in San Francisco in 1983: ten years later it was reported to have been celebrated in 44 different countries.⁵⁵ (In Malaysia — and presumably other Islamic countries — the reference to candles is deleted as sounding too Christian.) Other forms of memorializing those dead of AIDS include a display of cobble stones engraved with the names of those who have died from AIDS in several German cities, and the dedication to those deceased of the palm trees which line the centre of Santa Monica Boulevard in West Hollywood, California.

AIDS has also been recognized across the spectrum of more conventional 'high' culture, particularly in theatre and dance where the losses to the epidemic have been very considerable. Indeed one of the conventional responses to the epidemic has come to be the listing of cultural icons it has killed: Michel Foucault, Keith Haring, Rock Hudson, Liberace, Robert Mapplethorpe (whose dying was the basis of a moving story by Susan Sontag, 'The Way We Live Now'), Freddy Mercury, Rudolf Nureyev, Tony Perkins — and undoubtedly many others by the time this book goes to press. In many of these cases it was only their deaths through AIDS which made discussion of their homosexuality possible, and this in turn has helped reinforce the conflation of HIV and homosexuality in the public mind. The enormous impact of lesbians and gay men on Western culture has thus been discussed increasingly through the optic of the epidemic, with mixed consequences. (Where persons other than homosexuals have AIDS, their 'normality' is often stressed to the exclusion of all else, as was shown in Magic Johnson's much reported boasts that however he had contracted the virus it was certainly not through homosexual sex.)

As a story in *Newsweek* put it, these deaths 'become not just an occasion for grief but for politics'.⁵⁶ The article in which this quote appears became a litany of the losses to American cultural life due to AIDS — 'The impact on the arts and culture is incalculable', Gordon Davidson of Los Angeles's Mark Taper Forum Theatre is quoted as saying. 'The problem, aside from the horror of the deaths, is that the system by which

repertoire. Other countries have experienced similar losses, whether it be the passing of a number of well known writers in France, or the death of a well known pop singer in Malaysia, or of one of Australia's most revered conductors, Stuart Challender.

Challender announced both his illness and his homosexuality in a television interview shortly before his death, and there are numerous cases of artistic figures using their illness as a reason to publicly declare what had not been said before. Indeed, it is doubtful if the push to 'out' closeted homosexuals from groups such as Queer Nation would have emerged but for the impact of AIDS: both the focus on homosexuality, and the anger against people like Liberace, Hudson and Nureyev who refused to publicly discuss their illness, have been major factors in radicalizing those who believe in 'outing'.

More important for my purposes is the use of artistic channels to express a response to the epidemic. Just to catalogue the plays, books, films, art exhibitions and dance works generated by HIV would be a major project, and one beyond my resources: there is a symphony, John Corigliano's *First*, which was written as a response to AIDS and has been performed in several countries; a Requiem, the last work of composer Andrew Worton-Steward before his death from AIDS in 1990; and even an opera, Vittorio Furgeri's reworking of the story of *The Lady of the Camellias*, based on that most appropriate of operas, Verdi's *La Traviata*. Dance seems to have been a particularly rich field for the exploration of the meanings of the epidemic, particularly in the United States and in France where the director of the Festival of Montpellier has publicly committed himself to seeking out HIV-positive choreographers, and where condoms are included with festival programs.⁵⁷ Theatre has been particularly accessible to explorations of the meanings of the epidemic, so much so that a few years ago one British critic could begin a review by musing: 'I wonder which Shakespeare play will turn out to be about AIDS'.⁵⁸ A number of plays have been more directly inspired by the epidemic: Larry Kramer's *The Normal Heart*, William Hoffman's *As Is*, Tony Kushner's *Angels in America* have all been important contributions to the larger cultural understandings of the epidemic. And there is now a whole new genre of novels based on the experience, both personal and communal, of AIDS, with writers such as David Feinberg, Herve Guibert, Andrew Holleran, Adam Mars-Jones, Paul Monette, Oscar Moore, Sarah Schulman, and Reynaldo Arenas making AIDS central to their fiction: indeed, it is almost impossible to write of contemporary gay life without

novels — the quote is chosen almost at random — the sentiments are echoed in several shelves of contemporary writing:

Yesterday Martin and I attended a funeral. Though my first, it was just another in a progression for the other men; for a few it was a brief encounter with their own. We were, in a way, lucky, for there was no grieving lover, no one to lose control and offer useless bargains with death and, worse, to feel the undeserved guilt of a murderer or the unknowing betrayal of the murdered. There was none of that there, just friends to stand in for the last vigil in somber clothing. They were silent; by now they had become innured to words, even their own. At such moments they have strength only to wait for this to pass, in whatever manner it chooses.⁶⁰

The theatre and literature of AIDS largely reflects the responses of American gay men, and their works are read and played throughout the world in ways not true for cultural responses from other countries. This in turn can blind us to the specificities of the American experience; there has been a richer literary, theatrical and artistic response to the epidemic than one might guess from the lists usually cited. Nor are these responses confined to affluent Western countries; theatre has been an important medium for the discussion of AIDS in many parts of the world, though usually for educational purposes rather than the exploration of personal responses. However there are at least two Filipino plays, both staged by the Reachout AIDS Education Foundation, which deal with AIDS, and some theatrical responses have come from Brazil, Argentina and Zambia (where several theatre groups have been formed). (Reachout is a good example of a community group which was inspired by one strong personality — Jomar Fleras — who through sheer persistence has been able to obtain funding from groups such as AMFAR and the Levi Strauss Trust for a range of HIV educational activities.) In some African countries, such as Zaire and Nigeria, song has been a particularly important medium both for expressing the losses from the epidemic, and promoting messages of 'safe sex' and anti-discrimination. AIDS has been less evident in more 'Western' forms of writing; as the African Doumbi-Fakoly wrote: 'Despite the African writer's consistently close alignment with the concerns and desires of the people, they have curiously been

The American gay movement has been particularly critical of the failure of Hollywood to see AIDS as an issue to be addressed, and mainstream cinema has tended to refer to AIDS obliquely, as in the plague depicted in the film of the science fiction novel *Dune*, or in the current fashion for vampirism. (One of the best examples of the blending of myths around AIDS and vampirism is Dan Simmons' horror novel, *Children of the Night*, which manages to link the history of Dracula, AIDS orphans in contemporary Romania and science fiction speculation about retroviruses and immune deficiency.⁶² It is surely only a matter of time before it is filmed, combining as it does virtually every aspect of the modern horror/adventure story.) I suspect that AIDS is a sub-text to a considerable number of current films — the *Newsweek* story already referred to speculates that it may lie behind the fashion for films based on the return of the dead — and the success of Johnathon Demme's *Philadelphia* should ensure the subject will now enter mainstream cinema. In France, Cyril Collard's *Les Nuits Fauces* (1993), a film in which he played the HIV positive anti-hero and thus foreshadowed his own death shortly afterwards from AIDS, has received a number of the industry's main awards.⁶³ A number of non-mainstream films have, of course, been made about the epidemic, the first of which was probably Arthur Bressan's *Buddies*. Several of its successors, such as Gregg Araki's *The Living End* and John Greyson's *Zero Patience*, have been widely screened and reviewed.

The visual arts have been enormously rich in responses to the epidemic, and again responses — in the form of posters, painting, photography, performance pieces, etc. — come from almost all societies touched by AIDS. As I write, the washing machine contains T-shirts from Portugal, India, Thailand, Brazil and, of course, Australia, all bearing AIDS messages and imagery. One of the crucial roles of the visual arts is to challenge the dominant media images of the epidemic, which Simon Watney has identified as a diptych, 'which constantly narrates AIDS according to two sets of images: one focusing on color-stained electron microscope-derived images of HIV, usually misdescribed as 'the AIDS virus', and other signs of biomedical technology and authority; the other relentlessly constructing people with AIDS as 'AIDS victims', physically debilitated and preferably disfigured.'⁶⁴ Watney goes on to argue that:

In the case of AIDS, photographers are particularly well positioned to interrupt the crude flow of images that conflate HIV and AIDS and to challenge the crude and cruel version of the

than a medical diagnosis. For if we accept that photography participates in the practice of representation that forges our identities, we should be as sensitive to its potential to produce subjects as we are to its undoubted capacity to define objects.⁶⁵

There are many ways in which one can use 'culture' to discuss AIDS, from the polemics of Larry Kramer's play *The Normal Heart* to the inclusion of contemporary gay political images in Derek Jarman's film *Edward II* (and Jarman is one of those cultural figures who has made no secret of his own positive status). Between the films of Hollywood studios and the community activities of the Quilt there exist a vast range of cultural responses which include thousands of performers, writers, artists, etc.; many of them galvanized by the epidemic. People who have previously never thought of themselves as 'artists' have been pushed by the epidemic into artistic responses: one of the better known American performers, Tim Miller, describes himself as 'a loud obnoxious fag and all his various performances art agitating goes towards articulating a queer cultural identity and trying to find an artistic, spiritual and political response to the AIDS crisis'⁶⁶ This sums up very neatly the ways in which AIDS has broken down many of the traditional divides between art and politics — Miller boasts of having been arrested at a number of ACT UP protests, but having never missed a show from being in jail. Equally, one of the founders of the PWA movement, Michael Callen, has also used his musical skills to bring AIDS issues into popular music, both through his group The Flirtations and through solo performances.

There are a number of ways in which one might interpret the cultural responses to AIDS. At one level it is a subject which contains sufficient drama and emotion to capture the attention of artists, irrespective of their own stake in the epidemic. But what is striking about the great bulk of the response to date is that it grows out of the experiences of those most immediately affected; indeed, many of the writings and performances come from people who are themselves positive, and therefore writing/dancing/singing their own lives. More than in any case I can think of culture becomes a form of activism and demands to be judged on both criteria: most of the artists who are moved by AIDS are not content with just recording the impact of the epidemic, they wish also to have an immediate effect on how it is perceived and regulated.

Their work, too, for the most part grows out of their involvement in the affected communities. There are of course exceptions. (For example the fine Australian novel, Nigel Krauth's *J. F. Was Here*, which deals

community although the protagonist is homosexual.) But for the most part even artists using such formal forms as novels and symphonies credit their own involvement in the affected community as the inspiration and the motive for their work. Those working with more immediate forms, such as poster art or performance pieces, have become a cutting edge in much contemporary art, so that the graphics of ACT UP now enter into the catalogues of contemporary art (and, ironically, become commodities to be bought by the very elites they are assailing.)⁶⁷ Cultural workers, too, become major fund-raisers for AIDS organizations, and there have been some massive fund-raising efforts as in the Red, Hot and . . . concerts which have involved some of the biggest names in popular music and reached audiences of millions through global television coverage.⁶⁸ The joint concern with expressing an artistic response to the epidemic and raising money comes together in the New York-based Estate Project for Artists with AIDS, a project of the Alliance for the Arts.⁶⁹

There is a whole discussion which goes beyond my purpose here of the ways in which AIDS organizations make use of different cultural forms of education, support and, yes, propaganda: the ways in which, for example, HIV/AIDS has been written into the scripts of a number of soap operas requires analysis (both of content and of audience response) which is not largely available. Again, the global nature of mass communications makes this important across the world; a number of years ago I met a young man in Kuala Lumpur whose knowledge of HIV was largely based on having seen the US tele-movie *An Early Frost* on local television. National television in Trinidad and Tobago screened (in 1990) a six part series, *Tangled Lives*, commissioned by the National AIDS program, and dealing with the impact of AIDS on a particular family. Television and radio have told AIDS stories in countries as diverse as Zaire, the Philippines, and Israel.⁷⁰ Some educators have commented on the usefulness of puppetry and mime for raising delicate issues of sexual behavior: 'The puppet is one step removed from the human being, so puppeteering is not as threatening as using a human actor could be.'⁷¹

Contagious Desire: AIDS and Sexuality

All the cultural works discussed above touch in various ways on the new intersections between sexuality and death which AIDS has re-introduced into popular consciousness. The reality will vary enormously between different groups and countries: the meanings of AIDS for gay men in

Thailand or Tanzania. Yet in both cases there is the underlying sameness in that sexuality, a force linked with pleasure and reproduction, is once again — and more graphically than ever before — linked to danger and the prospect of death.

Communities most affected by the epidemic face the need to redefine sexuality in ways which can preserve sexual relations while protecting others from infection. This becomes an extraordinary dilemma for those who wish to have children; in many societies, where women's worth is measured by their ability to give birth, HIV infection means a life-threatening dilemma between risking pregnancy or denying the strongest social expectations of women. Even where the pressure to give birth is not enforced by the sort of social sanctions found in traditional African or Indian villages, the dilemma remains; many married men with hemophilia who were infected by HIV face strains on their marriage which were unimaginable before HIV. Moreover, certain traditional sexual practices — for example, in some African societies a widow is expected to become a second wife to her husband's brother — can have major consequences once HIV infection is involved.

Such dilemmas rarely present themselves in Western gay communities, although they may be a reality for individual homosexual men who may wish to father a child, and it has therefore been easier to integrate 'safe sex' into the mores of that community. To give up unprotected intercourse where there is no prospect of reproduction is, after all, rather a different demand to that where one of the central functions of intercourse is precisely to reproduce. Thus, while it seems true that gay men have changed their behavior more drastically than any other group, it would be silly to deny that they have also faced far less dilemmas than do other people, and I am somewhat sceptical of those who see the relative success of the gay community as a model for others. Comparatively few attempts have been made to develop 'safe sex' programs in ways appropriate for heterosexual intercourse; most programs have targeted women, as if the idea of persuading heterosexual men (who after all are required to wear the condom) were just too hard.

Only a few agencies have, like the Terence Higgins Trust in London, sought to 'eroticise safer sex for heterosexuals'⁷² As one feminist put it:

Even liberal approaches to AIDS education today . . . still endorse rather than question the most macho conceptions of sexuality. The aim of First AIDS [a program on Britain's ITV] was solely to force young men into condoms, enlisting the support of young women.

the more often the better, and sat back while the presenter ignored or mocked a few young men who were ready to explore the differences between macho mythologies and their own experience.⁷³

Yet even talking of condom use to many men is very difficult, and women who seek to initiate such discussion will often face rejection, abandonment and perhaps violence: 'For those women who are in abusive relationships, a characteristic which transcends racial, economic and social boundaries, the risk of introducing condoms may be more immediate than that of contracting AIDS.'⁷⁴

In the comparatively early days of the epidemic, particularly in Western countries, it was assumed that AIDS would lead to a more repressive attitude towards sexuality, and a rejection of sexual experimentation and adventure. A story on the filming of Brad Easton Ellis' novel *Less than Zero* written in 1987 could elucidate the comment that: '[It's] a kind of pre-AIDS book, so it has a different notion of sexuality than I think you can have now. Bisexuality, I don't think, is fashionable anymore.'⁷⁵ Six years later the comment seems somewhat naïve, and not because AIDS has gone away. Instead, a whole set of new discourses and practices have evolved, which incorporate a recognition of the need for 'safe sex' precautions to be made into a new form of eroticism. Examples of this approach to sexuality are found in phenomena such as the videos of Madonna, the growth of huge 'dance parties' such as those associated with Sydney's Gay & Lesbian Mardi Gras, the re-emergence of sex-on-premises venues in American cities — some catering to lesbians or heterosexuals as well as homosexual men — incorporating rules about safe sex. The possibility for such forms of sexual experimentation and adventure in the age of AIDS is not always well understood; a sophisticated commentator such as John O'Neill could still write (in 1990) that: 'to its credit the gay community has learnt that its sexuality cannot be played out in the anonymous intimacy and extraordinarily high rates of casual contact which were enjoyed in the bath houses',⁷⁶ ignoring that what is at issue is not the number (or names) of partners but the specific acts undertaken.

AIDS awareness has been incorporated into the mores of self-conscious gay communities, albeit unevenly (it is taking longer for an acceptance of condoms to become part of the sexual culture in parts of Southern and Eastern Europe which lacked the intense gay peer education programs of North America and Australasia.) Homosexual pornography

is largely American and French in origin... scenes of intercourse, although there was initial resistance to this move.⁷⁷ More interestingly, an awareness of AIDS issues now occasionally comes into the story-line, as in the US film *More of a Man*⁷⁸ which portrays an ACT UP activist as a role model for a confused young man (the final scene taking place during a Los Angeles Gay Pride parade.) Any awareness of a larger social or political world is sufficiently rare in pornography for this to indicate that the gay/AIDS politics of the current period has now been integrated into sexual fantasies in a quite remarkable way: 'the activist' now becomes defined as an object of desire, thus legitimating political activity at the level of the libido. This is a much more complex understanding of the realities of safe sex than the simple model of arithmetic decline pointed to by O'Neill.

Outside gay communities the challenge to incorporate an awareness of AIDS into the politics of sexuality and gender has only been outlined. But in different ways this is being attempted; the position of African women is enormously different from that of Western gay men, yet they too are beginning to discuss ways of changing community mores to make sex safer. Thus at an international conference on women and AIDS in Africa, participants recommended studies to better understand the nature and risks associated with polygamy and 'dry sex' (the practice whereby the vagina is dried before or during sex) and, perhaps over-optimistically, recommended that: 'The African concept of "maleness" needs to be re-evaluated in the face of what is known about HIV transmission, so that men's sexual behavior can be modified.'⁷⁹ As Maxine Ankrath has pointed out, this will require the empowerment of women as well as men, in order to build 'better social arrangements which lay a sound base for shared decision-making on matters of relationships, including sex.'⁸⁰

These examples suggest that AIDS has changed the understanding, construction and control of sexualities in ways that we are only gradually coming to understand, and which will vary enormously between different communities, countries and classes. As part of this, there is a slowly growing recognition that sexual behavior takes place within larger social, political, and economic constraints; speaking of Africa, Randall Packard and Paul Epstein wrote:

For sexual activity is not simply about pleasure. It is also about social reproduction. If efforts to control the spread of HIV infection do not include policies that deal with the underlying causes of both family separation and the high demand for family

To these factors might be added the need for a more sensitive understanding of the meanings of, and reasons for, prostitution. Too often, the discourses around HIV/AIDS present prostitutes as primarily a threat to the health of their clients, even though in many cases it is the reverse which is true: the sex worker is usually more vulnerable to infection than her more powerful customer. The ubiquity of commercial sex co-exists with a great deal of hypocrisy; even countries like Thailand, with its very extensive sex trade, pretends that it does not really happen. Where sex work is acknowledged, it is almost always conceptualized in terms of the threat posed by the sex worker, thus taking the onus off the client not to infect her or him, or to pass on infection to other partners. Many monogamous wives are at grave risk of HIV infection because their husbands visit sex workers, yet the prevailing discourses paint the workers, not the husbands, as the problem. Not only does this evade the issue of HIV transmission, it also fails to address the socio-economic conditions which give millions of people little option but to use prostitution as a means of short term survival.

The spectre of HIV has entered into the political economy of sexuality in ways ranging from the growing trade in young children for prostitution in many countries (where youth is seen as a guarantee of negative status), through complex and heart-breaking choices about pregnancy for women, to such 'post-modern' phenomena as safe-sex clubs and the fetishization of condoms in post-AIDS art. The increasing stress on understanding HIV as a sexually transmitted disease has opened up new spaces for talking about sexuality, and in this process has helped create new sexual identities (in many countries the use of terms such as 'gay and bisexual men' or 'sex workers' is a product of HIV/AIDS programs and surveillance). There is a current vogue for interpreting this as very much a product of Foucauldian-type discursive relations of power. I have real doubts about such analyses, as they seem to me to under-rate the role of people and movements — what sociologists often call human agency — in creating these identities for themselves, rather than being merely subject to the 'disembodied and ubiquitous processes' that some theorists attribute to (post)modernity.⁸²

It might be useful to postulate the term 'psycho-cultural' to pull together the very diverse ways in which AIDS has impacted on human life; the combination of these two terms, with their reference to the language of

individually and socially. (This sort of analysis needs to be thought of in conjunction with the more hard-headed studies by economists of the growing costs of the epidemic through its impact on production, labor, government, and household income.⁸³) It is no longer possible to collect all the media references to AIDS — indeed, even the books on the epidemic now fill a small library. The term, as much as the reality, has entered everyday life and shapes large numbers of social, cultural and sexual responses. We are all, in very diverse and varied ways, 'living with AIDS'.

Notes

- 1 *New York Native* (1985) March 25-April 7, p. 13.
- 2 For a discussion of some of these aspects of testing see Bayer, R. (1992) 'The Ethical Dimensions of HIV Testing' in Mann, J., Taranola, D. and Netter, T. (Eds), *AIDS in the World*, Harvard, University Press, pp. 747-59.
- 3 Tomasevski, K. (1992) 'AIDS and Human Rights', *AIDS in the World*, (note 2), pp. 559-61.
- 4 Daniel, H. and Parker, R. (1993) *Sexuality, Politics and AIDS in Brazil*, London, Falmer Press, p. 93.
- 5 From 1985 onwards, the *New York Native* maintained implacable hostility to the idea that HIV 'causes' AIDS. As late as mid-1993, its front page was proclaiming that the HIV Test is 'the mother of all medical scandals... unreliable, irreproducible, and possibly a total fraud', *New York Native*, 534, July 12, 1993.
- 6 Remarks by Haydee Emilia Pelligrini (1991) 'The Voices of People with HIV and AIDS', Proceedings of the Fifth International Conference for People with HIV and AIDS, London, p. 9.
- 7 Selection of documents by Brazilian NGOs regarding anti-HIV vaccines trials, Ronceod Pela-VIDDA São Paulo 1993. There is an early critique of vaccine trials in Africa in Patton, C. (1990) *Inventing AIDS*, London, Routledge, pp. 94-8.
- 8 Nussbaum, B. (1990) *Good Intentions*, New York, *Atlantic Monthly Press*, pp. 221-4.
- 9 Nussbaum, B. (note 8) p. 233.
- 10 See Merton, V. (1990) 'Community-based AIDS Research', *Evaluation Review*, 14, 5, October, pp. 502-37.
- 11 For an overview see Gilmore, N. (1991) 'The impact of AIDS on drug availability and accessibility', *AIDS*, 5 (suppl. 2), pp. S253-62. On Project Inform see Kwitny, J. (1992) *Acceptable Risks*, New York, Poseidon.
- 12 Crump, D. with Rolston, A. (1990) *AIDS Demographics*, Seattle, Bay Press, p. 13.
- 13 See Kramer, L. (1988) 'The beginning of ACTing UP', *Reports from the Holocaust*, New York, St. Martin's, pp. 127-36.
- 14 Gamson, J. (1991) 'Silence, Death, and the Invisible Enemy: AIDS Activism and Social Movement "Newness"' in Burawoy, M. (Ed.), *Ethnography Unbound*, Berkeley, University of California Press, p. 41.
- 15 *Ibid.*, note 24, p. 306.
- 16 Harrington, M. (1992) 'AIDS Activism and Drug Development', in *AIDS in the World*, (note 2), p. 239.
- 17 See Brown, P. (1993) 'The hour of the activist', *New Scientist*, April 3, pp. 14-15.

- 19 see Smyth, C. (1993) 'Fag Gags', *Burn*, Sydney, September, pp. 16-18.
- 20 Katz Miller, S. (1993) 'AIDS activists change tack on drugs', *New Scientist*, October 2, p. 4.
- 21 See McCaskell, T. (1989) 'AIDS Activism: The Development of a New Social Movement', *Canadian Dimension*, 9.
- 22 Rayside, D. and Lindquist, E. (1992) 'Canada: Community Activism, Federalism and the New Politics of Disease', in Krip, D. and Bayer, R. (Eds), *AIDS in the Industrialized Democracies*, Rutgers, University Press, p. 49.
- 23 See Carr, A. (1990) 'Trials and tribulations: cutting the HIV treatments knot', *Outrage*, November, Carr, A. (1991) 'HIV drugs: Howe fails the big test', *Outrage*, March.
- 24 See Paton, C. (1990) *Inventing AIDS*, London, Routledge, pp. 162-3 (note 16).
- 25 For example, Gilbert Herdt. See, Herdt, G. (1992) 'Culture, History and Life Course of Gay Men' (with Andrew Boxer), in Herdt, G. (Ed.), *Gay Culture in America*, Boston, Beacon, p. 13.
- 26 Herrell, R. (1992) 'The Symbolic Strategies of Chicago's Gay and Lesbian Pride Parade' in Herdt, G. (note 25), p. 247. On the original 'caps' see Altman, D. (1993) *Homosexual: Oppression and Liberation*, New York, New York University Press (new edition), chapter 4.
- 27 Mohr, R. (1992) *Gay Ideas*, Boston, Beacon, pp. 50-3.
- 28 Salmen, A. (1991) (Ed.), *ACT UP: Four Utern Aitch*, Berlin, Deutsche AIDS Hilfe.
- 29 See Wachter, R. (1991) *The Fragile Coalition*, New York, St. Martin's, for an account of the role of ACT UP in the 1990 San Francisco International Conference.
- 30 'Sloppy' and 'depressing' Berlin conference', (1993) *Man to Man*, Auckland, August 5, p. 12.
- 31 See Gallagher, J. (1993) 'When the Spotlight Dimms', *The Advocate*, January 12, pp. 57-9; Schmalz, J. (1993) 'Whatever Happened to AIDS?', *New York Times Magazine*, 28 November.
- 32 Schuklenk, U. (1993) 'AIDS Research and Censorship', unpublished manuscript. See Table 9.24 in *AIDS in the World*, (note 2), pp. 440-1.
- 33 Padgug, R. and Oppenheimer, G. (1992) 'Riding the Tiger: AIDS and the Gay Community', in Fee, E. and Fox, D. (Eds), *AIDS: The Making of a Chronic Disease*, San Francisco, University of California Press, p. 268.
- 34 Kayal, P. (1993) *Bearing Witness*, Boulder, Westview Press, p. 7.
- 35 For two early comments on these tensions see Dalton, H. (1989) 'AIDS in Blackface', *Dandelion*, Summer; Deredewicz, W. (1988) 'Against All Odds: grass roots minority groups fight AIDS', *Health/PAC Bulletin*, Spring.
- 36 See van Herten, A. (1993) 'No end seen in the battle over D.C.'s AIDS funds', *Washington Blade*, 24, 30, July 13-19; Chibbaro, L. (1993) 'Accusations fly after Ryan sacking', *Washington Blade*, 24, 31, July 16.
- 37 In an announcement for the Forum, 'A Question of Parity', Los Angeles, July 1993.
- 38 See Hammonds, E. (1992) 'Missing Persons: African American Women, AIDS and the History of Disease', *Radical America*, 24, 2, 'Race, Women and AIDS' (1990) in *The ACT UP/New York Women and AIDS Book Group: Women, AIDS and Activism*, Boston, South End Press.
- 40 See Stewart, C. (1991) 'Double Jeopardy', *New Republic*, December 2; and Page, C. (1991) 'Deadly Silence', *New Republic*, December 2.
- 41 Alback, E. (1992) 'Denmark: The Political "Pink Triangle"', in Krip, D. and Bayer, R. (Eds) *AIDS in the Industrialized Democracies*, New Brunswick, Rutgers University Press, p. 312.

- 43 D. and Bayer, R. (see note 41), p. 121.
- 43 'Ten Years of Touching Lives' (1991-1992) Annual Report AIDS Project, Los Angeles, p. 8.
- 44 Paton, C. (1990) *Inventing AIDS*, New York, Routledge, p. 21.
- 45 See, for example, Kayal, P. (1993) *Bearing Witness*, (note 35), p. 233.
- 46 Freud, S. (1917) 'Mourning and Melancholia', in Strachey, J. (Ed.) (1957) *The Complete Works of Sigmund Freud*, London, Hogarth Press, vol. 14, pp. 244, 246.
- 47 See Bronski, M. (1989) 'Death and the Erotic Imagination', in Preston, J. (Ed.), *Personal Dispatches: Writers Confront AIDS*, New York, St. Martin's; Crimp, D. (1989) 'Mourning and Militancy', *October*, 51, Winter.
- 48 Holleran, A. (1986) 'Friends at Evening' in Stambolian, G. (Ed.), *Men on Men*, New York, New American Library, p. 95.
- 49 Musoke, D. (1992) 'A community fights back', in *The Hidden Cost of AIDS*, London, Panos Dossier, Panos Institute, p. 50.
- 50 Reid, E. (nd) *The HIV Epidemic and Development: The Unfolding of the Epidemic*, New York, UNDP, p. 10.
- 51 See Ruskin, C. (1988) *The Quilt: Stories from the NAMES Project*, New York, Pocket Books.
- 52 Paton, C. (1988) 'No Turning Back', *Zeta magazine*, Boston, January, p. 70.
- 53 Sturken, M. (1992) 'Conversations with the Dead', *Societal Review*, 92, 2, April-June, p. 77.
- 54 Blazey, P. (1993) 'Grief Queens and Primal Screams', *Outrage*, 122, July, p. 48.
- 55 'Candlelight Memorial 93', *The Act, Action for AIDS*, Singapore, 6, p. 1.
- 56 Ansen, D. (1993) 'A Lost Generation', *Neuroseek*, January.
- 57 'Dans le monde de la danse, les tabous sont dejus tabous' (1993) *Le Journal de Genere*, January 7.
- 58 Williams, H. (1987) 'Rather Shocking', *New Statesman*, June 19, p. 25.
- 59 Altman, D. (1993) *The Comfort of Men*, Melbourne, Heinemann.
- 60 Peck, D. (1993) *Fucking Martin*, London, Chatto & Windus, p. 158.
- 61 Doumbi-Fakoly, (1992) 'African Literature: Witness to its Time', in Klusacek, A. and Morrison, K. (Eds), *A Leap in the Dark*, Montreal, Vehicule, p. 225.
- 62 Simmons, D. (1992) *Children of the Night*, London, Headline.
- 63 Mabry, M. (1993) 'A Fatal Attraction', *Neuroseek*, March 22.
- 64 Watney, S. (1990) 'Photography and AIDS', in Squiers, C. (Ed.), *The Critical Image*, San Francisco, Bay Press, p. 187.
- 65 *Ibid.*, p. 192.
- 66 Flyer for *My Queer Body*, a performance piece by Tim Miller, Sydney, February 1993.
- 67 On ACT UP graphics see Crimp, D. with Rolston, A. (1990) *AIDS Demographics*, Seattle, Bay Press.
- 68 The first of these was Red, Hot and Blue in 1990, using the songs of Cole Porter. See interview with Leigh Blake by Yves Averous (1991) *Outrage*, February, pp. 31-3.
- 69 See Report, *The Estate Project for Artists with AIDS*, New York, Alliance for the Arts.
- 70 See Piotrow, P., Meyer, R. and Zulu, B. (1992) 'AIDS and Mass Persuasion', in *AIDS in the World*, (note 2), pp. 733-47.
- 71 Mivase, M. with Friedman, G. (1992) 'Puppets against AIDS', in *A Leap in the Dark*, (note 61), p. 277.
- 72 For a comment on the programme see O'Keefe, I. (1989) 'Nouvelle sex', *New Statesman & Society*, March, pp. 14-15.
- 73 Segal, I. (1987) 'AIDS is a Feminist Issue', *New Socialist*, London, April, p. 9.
- 74 Marvellous Mhloyi, (1993) 'Can a New Sex Culture Save the Next Generation?', *National AIDS Bulletin*, July, p. 19.

- August 30, p. H14.
- 76 O'Neill, J. (1990) 'AIDS as a globalizing panic', *Theory, Culture & Society*, 7, p. 335.
- 77 See Speck, W. 'Working with the film language of porn', in *A Leap in the Dark*, (note 61).
- 78 *More Of A Man*, a video by Jarry Douglas Scabag Production, 1990.
- 79 'Summary and Recommendations' (1991) Society for Women and AIDS in Africa: Third International Conference on Women and AIDS in Africa, Yaounde, Cameroon, November 19-22.
- 80 Ankrab, E. M. (1991) 'AIDS and the social side of health', *Social Science and Medicine*, 32, 9, p. 972.
- 81 Packard, R. and Epstein, P. (1992) 'Epidemiologists, Social Scientists, and the Structure of Medical Research on AIDS in Africa', *Social Science and Medicine*, 33, 7, p. 776.
- 82 This phrase comes from Gamson, (see note 14), p. 53.
- 83 See, for example, Bloom, D. and Lyons, J. (1993) *Economic Implications of AIDS in Asia*, New Delhi, UNDP; Devereux, S. and Ecle, G. (1991) *Monitoring the Social and Economic Impact of AIDS in East and Central Africa*, Oxford, Oxford University Press.

Chapter 5

The Evolution of the Community Sector

With success comes change, and not always for the better. In an early evaluation of GMHC's organization development plan, the consultant wrote:

When I met with two of the staff at the Mayor's Voluntary Action Council, I explained to them that I was having a hard time finding models of large scale, crisis oriented, grass roots volunteer organizations that had successfully made the transition to a stable organization without changing their fundamental culture or delivery of services. They responded that the models don't exist because this is almost never accomplished.¹

In both developed and developing countries there are now large AIDS organizations which have grown in a few years from being volunteer-run small organizations, dependent mainly on resources raised from their own communities, to large, professional service organizations, funded by either state, international agencies or major donors, and controlled by paid staff rather than members or volunteers. (Note that in developing countries, many organizations originate with a small number of paid staff, and may then seek to develop processes of inclusion for both clients and volunteers.) Perhaps the comment of one executive officer of a large American AIDS organization who told me that he tried to make sure his Board members rarely entered the building is extreme, but he was articulating a commonly heard feeling that 'the professionals know best'. A more sensitive assessment of the shifts came from Christopher Spence, director of London Lighthouse, who spoke of struggling 'with the relationship between the early unpaid pioneers and the first professional paid staff; with the balance of power between those who use the services and those who

minority, and the substantial majority of volunteers on whose contribution the success of the project hinges.²

To some extent it is inevitable that as organizations grow they will become reliant on paid staff, and the early leadership will be supplanted by a new generation of professional managers. (There are echoes here of a Weberian shift from charismatic to bureaucratic authority.) But there are costs to these changes. Organizations which grew out of affected communities come to lose their ties with those they claim to represent, while moving almost inexorably into a dependent relationship with government and/or foreign donor agencies which makes them neo-agents of the state. As Carlos Caceres has written, reflecting on the trajectory of Latin American HIV/AIDS groups:

Many southern NGOs, started by intellectuals or professionals with some emotional interest in particular issues and with different degrees of social commitment and sophistication in their critical analysis and strategies... tend at some point to implicitly reformulate their focus in terms of self-legitimation and consolidation of their institutional power... Groups lose the initial focus on the development of services for persons with HIV and adopt a self-legitimizing narcissistic strategy, losing self-critical capacity and turning their attention to the possibilities of funding for organizational stability.³

The trajectory hinted at by Caceres is the subject of an important paper by John Maclachlan, who writes out of his own experience as a positive man who was very involved in the development of London Lighthouse. Maclachlan sees the essential role of community organizations as involving the empowerment of those most affected, defining empowerment as 'becoming aware of oneself as a totality, a whole and integrated personality fully able to establish clear positions about oneself and one's life, to take control over what happens to oneself, and to take responsibility for one's positions, actions and feelings'.⁴ He argues that the original 'owners' of self-help groups — namely people with the virus — have handed control over to professionals, and in the process have allowed themselves to become disempowered: 'What was a self-help movement gave rise to an industry, and the perceptions, needs and demands of the various components of that industry have, mostly unintentionally and partly through the acquiescence of people with the virus, diverted what the self-help movement was all about'.⁵ At the same

exhaustion, illness and death amongst the original founders of the movement have all contributed to the decline of their original commitment to empowerment and participatory control.

As the demand for services expands, organizations come to seek respectability in the eyes of funders and governments, which in turn means they may distance themselves from their original constituency, as when staff of the Terrence Higgins Trust were quoted as denying its gay character.⁶ Some organizations fail to make the required transition, as seems to be the case for Frontliners, a British group which was set up to provide support and advice for positive gay men. It collapsed in 1991, and an evaluation of its collapse suggested that: 'Frontliners found to its cost, like many other voluntary organizations, that the qualities of founders (commitment, enthusiasm, courage and determination) are often not the qualities best-suited to the people needed to lead and manage organizations once they have developed and grown.'⁷ Similar problems beset the apparently very successful San Francisco organization, Shanti, first in 1988 when its founder, Jim Geary, was forced out,⁸ and then again in 1993 when it lost its housing contracts with the City of San Francisco. But even the apparently successful organizations have seen what seems an inexorable decline in the role of volunteers and Board members in policy direction and control, and pressures to operate in the mould of more mainstream agencies.

In one of the few analytical pieces which have appeared on AIDS organizations, Suzanne Kobasa drew on the work of sociologist David Sills to point to 'potential dissonance' within Gay Men's Health Crisis. Sills distinguished between 'formal organization-like associations' and 'social movement-like associations'. As Kobasa writes:

When considered in the broad context of all American voluntary associations, GMHC clearly has to be placed within the social-movement-like half of the world. Its formal mission contains the goal of advocacy and policy change. Its volunteer participants typically bring high levels of emotional commitment to its work... Viewed in the light of its own history, however, the current structure of GMHC reflects some of the characteristics of a formal-organization-like association. Increasing institutionalization and formalization have accompanied the growth of GMHC, whose staff payroll totals 140 people.⁹

By 1993 the staff at GMHC had increased to 230, and the agency was

part because of their perceptions of powerlessness.¹⁰

Underlying these shifts is the fact that the epidemic itself is changing, and that the demands on community organizations both develop and escalate. Other than a few groups in Africa which grew out of the immediate needs of those who were already sick, most AIDS organizations arose at a time when the case load was low, and prevention education, advocacy and support for those who were positive (but not necessarily sick) seemed the major priorities. As more and more people fell ill — often including those involved in establishing these organizations — the demands and the stress on the organization increased. (Between 1989 and 1992 the Toronto PWA Foundation reported a 200 per cent demand for support services, and a 9 per cent increase in federal funds.¹¹) In some of the older groups most of the founders have already died, and massive grief and loss is a reality of life for many staff and volunteers. (This is one of the themes Larry Kramer foreshadowed in his play *The Normal Heart* written early in the history of the epidemic.) The burden of frequent hospitalizations and funerals, involving staff and key volunteers, places a burden on AIDS organizations which is near unique for Western community organizations, at least in peace time.

Simultaneously, advances in the medical management of HIV/AIDS have meant a prolongation of life for people who are sick — at least if they have access to high technological medical care. Inevitably and rightly there is a new emphasis on issues of access to treatment which is sometimes posed as competing for resources with prevention interventions. Where the latest advances in medicine are unlikely to be available, as in most of the developing world, issues around care for the dying and, even more dramatically, their surviving children are equally crucial, though even more difficult to resolve. Many groups have travelled the route of Pink Triangle in Malaysia, which in itemizing its goals for development in 1989 could list six, none of which included treatment or support for those who are sick. Within two years, these latter goals had become important ones for the organization.¹²

The Creation of National Networks

In only a few countries are there effective national networks embracing all — or even the bulk — of community-based AIDS organizations. Where these have been created, this is often, as in the case of Australia and Germany, partly at the instigation of central governments eager to

Society was established somewhat later, but has become a significant national body. This is probably also true of France, where, despite the existence of a number of other groups, AIDES is the *de facto* national community peak organization. Other Western countries such as New Zealand are sufficiently small that one peak body (the New Zealand AIDS Foundation) can both represent the most affected community nationally and provide direct services at a local level. In other countries, such as the United States or India, it has proven very difficult to establish any meaningful national peak body. In the United States, the importance of local and state governments means that there is less need for this than is true in more centralized systems, and the first attempt at creating a national grouping, the National AIDS Network, collapsed in 1990. Since then the AIDS Action Council, which includes over 1100 members and is mainly funded by its larger member organizations, acts as a national lobbyist and resource group, largely driven by the largest local organizations such as GMHC and APLA.

In a number of developing countries high priority is attached to creating a strong national network by community groups, who argue that the need for a common voice for the community sector is the only way they can impact on government and donor agency policies. Thus in Chile, a couple of seminars, funded by the PANOS Institute, were used to pull together a coalition of organizations doing work on HIV/AIDS, which established an on-going network with (in mid-1993) nineteen organizations as members. The Chilean case is seen by some donors as a model for other Latin American countries. Malaysia has a broad coalition of non-government groups doing HIV/AIDS work, and there are similar networks in Thailand and the Philippines. Note, however, that the Malaysian Council of NGOs on AIDS has a far broader membership than is usually assumed in Western community networks, including the Malaysian Medical and Dental Associations alongside Pink Triangle and the Community AIDS Service Organisation Penang, which restricts both the knowledge and the commitment of the network. Elsewhere networks will also include major international NGOs operating in the countries, as is true of the Zimbabwe AIDS Network or the NGO Consortium in Kenya.¹³ A more political path has been followed by the South African AIDS Consortium, whose first project on its establishment in 1992 was to adopt a 'Charter of Rights and Duties on AIDS and HIV', 'designed to combat human rights abuses affecting both individual rights of dignity and autonomy, and unequal and discriminatory allocation of resources'.¹⁴

In the absence of government support and resources it is very difficult

community-based groups, which by their nature are local in character, both geographically and in terms of their constituencies. Hector Carillo has pointed to the competition which exists between various AIDS groups in Mexico, often expressed through strong ideological differences, which is a common problem in Latin America: '... Each group's legitimacy becomes peculiarly dependent upon the public perception that they are in the vanguard of the struggle. To consolidate, then, is to surrender their identity to popular appeal.'¹⁵ Without an incentive to consolidate, an incentive that may need to be both carrot and stick, the individual needs of each community organization to establish and strengthen its particular identity will tend to over-ride the vaguer benefits of national cooperation.

The Australian Case

Developments in Australia are interesting as a case study of what can be done within a favorable environment (and with some resources) for community AIDS organizing. Over a fairly short period of time during 1984-1985, AIDS Councils were established in all six Australian states plus the two mainland territories. In all cases these were established in the state capital cities, which are also the major population centers, and in all but a couple of the smallest centers they grew out of initiatives taken by the local gay communities. Unlike developments in Denmark and The Netherlands, which also had largely sympathetic governmental and social environments, there was a clear decision to establish new organizations, rather than to add HIV/AIDS work to the mandate of existing gay groups. (While the existing Dutch national gay group COC remained a significant factor in AIDS services, the Dutch government also established local 'platforms' that brought together municipal health services, health carers and community organizations in local areas.) The apparent uniformity of development between states owes a lot to the willingness of the federal Labor government to provide funding for such organizations in conjunction with state and territory governments; in the case of the ideologically homophobic government of Queensland, the federal government made a special arrangement with a local Catholic order (which ran one of Brisbane's major hospitals) to act as a conduit for federal funds.

Particularly in the three largest Councils — those based in Sydney (the AIDS Council of New South Wales, ACON), Melbourne (the Victorian AIDS Council, VAC), and Brisbane (the Queensland AIDS

were impassioned in their sense of urgency and commitment, and who enjoyed and bullied others, many of them veterans of already existing gay organizations, to accept positions of responsibility in the new organizations. As increasing amounts of government monies became available, full time staff were hired, and new tensions between volunteer boards and professional staff developed. An acceptance of partnership between the state and the voluntary sector has led to the creation of a new species of 'AIDSocrats', namely people (largely, but certainly not only, gay men) from the voluntary sector who have moved into professional jobs involved in managing the epidemic. (The term is taken from that Australian invention, the 'femocrat'.)¹⁶ Thus in Victoria the funding President of VAC took a state government job, and became responsible for the management of a number of government AIDS programs; the first two Presidents of ACON, both academics, were replaced by a librarian who in turn resigned from the voluntary Presidency to become Education Manager and subsequently Executive Director of the organization; in Queensland the foundation President moved into a government sector AIDS job though only after holding the office of President for a number of years.

As the staff establishment of the AIDS Councils grew, the most common place for staff recruitment was among volunteers; many of the staff of VAC have been volunteer Board members in the past. Meanwhile 'AIDS-ocrats' in other organizations came to play a leadership role in the Councils, so that, for example, a two-term President of ACON simultaneously held a series of research/management jobs in AIDS. Again, because of the particular nature of state/community sector interaction in Australia (matched only, to my knowledge, in The Netherlands), many of the managers of AIDS Councils also sit on government bodies, where their peers are often state sector bureaucrats rather than the volunteers from their own community. There are some cases where community and state sector bureaucrats have sat on employment interview panels for positions in each other's organization.

This development has co-existed so far with the continued growth of the volunteer component of AIDS Councils, but the role of volunteers has changed, and has moved away from being one of providing policies and control to that of supporting and servicing programs determined increasingly by full time 'AIDS-ocrats'. While there was always a large volunteer base who were primarily concerned with care and support for those with the virus, the early years of the AIDS Councils also depended on volunteers for the great bulk of policy and program development. As

programs have grown with it, volunteers are increasingly being defined in the traditional ways of established charities: volunteer-led organizations have become professionally-led organizations with a large pool of volunteer support.

There are of course real attempts to preserve some sense of empowering volunteers. All the Australian AIDS Councils are controlled ultimately by elected Boards. (This is in contrast to their American counterparts where in general Board members are selected, usually by the existing Board. The authoritarian structure of large US groups was reflected in the determination of ACT UP to run itself along lines of participatory democracy.) The Victorian AIDS Council has a membership-elected Board, responsible, in the neat phrase of the General Manager, for 'governance not management',¹⁷ and an elaborate structure of program areas, where elected Convenors and staff Managers work together, and where, in theory at least, policies are developed by volunteer working groups. When this works well it preserves a sense of ownership, and has had a major impact in developing considerable loyalty to the organization. ACON, which has had to deal with a far larger epidemic, is much less reliant on such volunteer input, although it does have a handful of individuals who have played key roles in policy development. (It should be noted that the democratic structures of VAC work essentially in Melbourne, where almost three quarters of the state's population live. It has been more difficult to find ways of creating meaningful participation in any but support programs for those members who live in provincial and country areas.)

Precisely because the staff of AIDS organizations — I am now generalizing from the above examples — often come from those most affected, many will find it difficult to distinguish between their professional and their community interests. What might seem to others as a unionist insistence on staff prerogatives will often seem to those adopting these positions as a vital element in the common struggle. As organizations develop, staff will inevitably come to have greater resources available to them in terms of knowledge, time and access, and this in turn will act so as to disempower volunteers and even elected Boards and executives.

To some extent the bureaucratization of Australian AIDS organizations is the inevitable consequence of government recognition and funding. Such support comes with demands for accountability which can only be provided by paid staff and professional management. The danger is that what were community-based organizations in a full and organic sense become more like cheap-rate state bureaucracies, with only a

Participatory democracy, which is an element of genuine community control, means constant change and a willingness to take risks, and this is something that sits badly with the requirements of bureaucracy and staff tenure. ('In one sense', one community organizer has said, 'All organizing is reorganizing. There has to be that ability to go in and shake things up.'¹⁸)

Certainly, the growth in staff resources may provide the best level of professional services. It does not, however, assist in community development and empowerment, nor does it preserve the political base that will be required if the Councils find themselves under political threat or lose considerable funding as happened to the British community sector in 1993.¹⁹ In a revealing, if perhaps too cynical comment, Nicholas Bates has written that: 'Glossy posters, brochures and T-shirts have become a traditional and expensive feature of the larger AIDS Councils' education campaigns. Increasingly, it could be argued, these campaigns have less to do with community participation and more to do with supporting corporate images that AIDS Councils are being encouraged to adopt.'²⁰

A much angrier attack on mainstream AIDS agencies appeared in a Los Angeles 'gayzine' which claimed large scale misappropriation of funds and proclaimed: 'DO NOT GIVE TO THESE ORGANISATIONS. You are paying plane fares and lunch tabs.'²¹ Such claims have dogged all voluntary and community organizations and are very difficult to answer: usually they refer to the collision of two logics, in this case an argument that monies should go directly to those with AIDS as against supporting the professional staffs whose expenses for what they would claim as legitimate lobbying and representative work easily becomes an object of resentment to grassroots workers. I remember defending a former VAC President against bitter claims that he was always interstate on junkets; his critic was both unaware and uninterested in the fact that these were trips paid for by government which enabled him to sit on national bodies as a gay community representative.

The Australian developments are exemplified by developments in the peak organization, the Australian Federation of AIDS Organizations (AFAO). AFAO owes its existence to the desire of the federal government to have one national body representing the community sector with which it could negotiate, and it is essentially a federation of the eight state and territory AIDS Councils, plus three mini-peak bodies representing People With AIDS, sex worker, and drug user organizations. (To differing extents these groups are represented within local Councils, and the latter two groups have, of course, a number of priorities which are not HIV-

related. It is not surprising therefore that relations between them and the AIDS Councils, who see themselves as the 'real' constituency of AFAO, have been difficult.) There are some clear parallels in the creation of the Deutsche AIDS Hilfe in another federal system, (West) Germany.²² The demarcation of responsibility between the central body of the AIDS Hilfe and its one hundred plus local groups is similar to that in AFAO, although the lack of large scale state bodies has placed greater demands on the central Berlin office.

AFAO is nominally controlled by a committee, consisting of two delegates per constituent, and an elected Executive. In most cases the Executive Officers and local AIDS Councils will be one of the two committee delegates, and they will also tend to remain involved much longer than volunteer members (usually Council Presidents). The result is that the AFAO Committee has become a *de facto* organization of managers, which reflects a bureaucratic rather than an activist view of politics. This is symbolized in the first three Presidents (all gay men) of AFAO. The first, though a doctor with an HIV-caseload, came out of the voluntary sector and was one of the founders of the Gay Men's Health Clinic, established by VAC partly because of the state government's then support for community health centers. (Note that the full name of the organization is Victorian AIDS Council/Gay Men's Health Center. This is a mouthful for receptionists, and I have avoided it here in the interests of brevity.) He was replaced in 1990 by the former Executive Director of ACON, and in 1992 AFAO chose someone whose background was that of a senior advisor to Health Minister Blewett but who had no experience as a volunteer in a community AIDS organization. (He, in turn, was succeeded by a former volunteer President of VAC; I would not want to claim that the process of professionalization is inexorable. However this latest change coincided with a decline in AFAO's budget and access to federal government.)

There is no judgement intended of the three individuals in noting that this progression reflects something of the increasing incorporation of the community sector into the state. In the immediate term this has certain strengths: former advisors to governments bring with them considerable knowledge of how the system works and remarkable access to politicians. But there is an accompanying loss, which is the roots in community activism, and a willingness to accept the imperatives of government in order to push the agenda of the community. It is probably true that to date this acceptance has made possible certain real and important gains, and the Australian community movement has been remarkably lucky in that, at least at a federal level, it has dealt throughout the epidemic with a Labor government in which there have been powerful and well-informed allies.

Nonetheless, the experience of AFAO poses the classic problem for any community organizations which need work with government: is it possible to retain a genuine intellectual and political independence without so antagonizing the government that one loses essential support and funding? In the United States, this dispute has been played out in very bitter disputes between groups such as ACT UP and Queer Nation on the one hand, and the establishment AIDS and lesbian/gay groups (e.g., the National Lesbian & Gay Task Force) on the other.²³ In Australia this bitterness is not nearly so apparent, although it occasionally surfaces in criticisms of the AIDS Councils/AFAO as being too close to government. In the long term, however, the danger is of a slow slide towards co-optation into the role it suits governments to accord the community sector, while losing the political base and intellectual analysis to oppose this shift.

Individuals, Communities, Bureaucracies

The same imperatives are at work even where governments are far less generous and willing to accord recognition to the community sector than in Australia. Indeed, the experience of groups in the United States suggests that the pressure to be acceptable to potential private donors can sometimes be even more restrictive than dependence on the government where it is easier to mobilize support through the political process. (No major AIDS organization in the US receives a majority of its funds from government. Even in San Francisco, where the city/county authorities have been far more supportive than most, the San Francisco AIDS foundation gets almost 70 per cent of its funds from private sources. Certainly the absence of central government support and funding for a peak community body means that there is less of a voice able to speak for the affected communities in Britain than in such federal systems as Australia, Canada and Germany: Richard Freeman quotes two German researchers who have suggested that 'unitary political systems tend to have dealt with AIDS by developing programmes within their existing administrative structures, while those with fragmented health policy systems take more direct account of those to whom policy is addressed.'²⁴

We should not make too much of this comparison however: if we were to take as models the United States and New Zealand we would end up with a quite different conclusion. The British situation seems to result more from decisions to give policy control over HIV/AIDS to mainstream civil servants and medics than to structural differences in government systems. (The dominance of Thatcherism — that combined hostility t

particularly if associated with the sort of people associated with AIDS — meant much less British government money for AIDS organizations than was true for most northern European countries; the largest British organization, the Terrence Higgins Trust, has always covered at least half its costs through fundraising activities.) The complex ways in which health services were reorganized under Thatcher meant an increasing emphasis on competitive tendering for contracts, which by its nature puts extra administrative demands on community organizations, thereby forcing an increase in time spent meeting the demands of various contracting authorities. As John MacLachlan has pointed out: 'The contract culture enables the customer (the funding body) rather than the consumer (people directly affected by AIDS) to dictate more specifically the nature and shape of services to be provided.'²⁵ Similar systems operate in the United States and New Zealand, though not to the same extent as in Australia or most of Europe.

The Australian case is not dissimilar to that found in some other rich countries where government funding has helped the development of a significant community sector: there are clear similarities in both Canada and Germany. But even in those countries that are both far poorer and where governments have been much less supportive of the community sector, one can trace similar itineraries in the short history of AIDS organizations. Groups tend to begin because of a particular charismatic and driven leader, whether it be Larry Kramer in New York,²⁶ or Natee Teeraratjanapongs in Bangkok (founder and driving force of FACT), or Ashok Row Kavi, whose paper *Bombay Dost* has been the basis for building a gay community and for AIDS work among homosexual men in India. As the organization grows it becomes more genuinely based in a particular community, leading to an influx of new volunteers. At this point the original founders are sometimes pushed aside — as happened to Larry Kramer in GMHC — or alternately become full time workers for the organization. (In the case of developing country organizations there is yet a further possibility: the founders become so well known overseas that they spend more and more time doing international work, which necessarily distances them from their constituency at home. Meanwhile others — perhaps more driven by ambition than conviction — see in AIDS a burgeoning area in which to make careers and win patronage from donor agencies.)

As organizations grow they start to seek external funding and with this comes the professionalization and bureaucratization already referred to, and further change in leadership. Early leadership, which is based on personal commitment and inspiration, is replaced by those with

to be supplanted by that of full time staff. Just as in the early days, organizations may be dominated by a single figure, but in this case it is usually an executive director legitimized by position rather than a charismatic leader whose control is based on personal politics. In just under a decade the most recognized spokesman for the Victorian AIDS Council has moved from its founding President, a long time gay activist, to an elected President, who came out of a VAC's Support program, to the General Manager, an appointed position whose present incumbent has already worked with three Presidents.

VAC epitomizes the confusion around control found in most CBOs in that it combines, uneasily, concepts of authority based on competing models of representative democracy, of volunteer control, and of managerialism or control by staff.²⁷ The first is expressed through a Board elected by the membership of the organization; the second through Program Management Committees, made up of active volunteers, which nominally make policy in their particular area; the third through the existence of a General Manager and a number of program managers. Clearly there is potential here for conflict between individuals justifying their actions by reference to different sources of authority, and defining areas of responsibility and control is an ongoing theme in the organization. Not surprisingly, tensions between staff and volunteers (including the Board) over who really constitutes the organization remains a powerful underlying script in the organization. Among staff there are tensions as well: the creation of a managerial strata has meant some internal tensions, with many staff adopting a strong unionist stance *vis-à-vis* both managers and Board, while simultaneously claiming to be part of the same community. That this may make the traditional unionist position towards management and owners inappropriate has not been largely recognized within the organization.

These are by no means issues limited to AIDS organizations. Indeed, one study of the environmental movement in the United States has discussed these very problems: 'For social and political movements to remain dynamic, the organizations that comprise them must strive to maintain the spirit and vigor of volunteerism even as they become increasingly professional in their management. It is often the active corps of volunteers and amateurs who keep organizations from becoming tired old bureaucracies.'²⁸ Nor is it a concern restricted to rich countries. External funding has helped a rapid growth of staff in at least some developing country organizations, such as TASO or the South India AIDS Action Programme, and this creates its own constraints.