Social Aspects of AIDS

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Power and Community
Organizational and Cultural Responses to AIDS

Dennis Altman

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Chapter 1

HIV and Community

It should no longer be necessary to stress the significance of the growir
HIV/AIDS epidemic. Too many of us have experienced first hand tl
pain of watching young people suffer and die, are ourselves positive, (
have experienced the illness and loss of lovers, friends, and family. Wh
only a decade ago seemed the exotic disease affecting a handful of urba
male homosexuals in the United States is now threatening to become
global pandemic, devastating not only gay and hemophilia communiti
but also whole regions of Central and East Africa, the Caribbean, Sou
and South-east Asia.

In affluent countries the AIDS epidemic hit a generation who ha
come to believe that the spectre of infectious disease not susceptible
medical treatment and prevention was a thing of the past. But as tl
prognosis for medical intervention comes to be more optimistic for tl
minority of the world's population with access to modern medic
technology, HIV is becoming yet another threat to life in developir
countries. Unlike other diseases with which such countries need contend
AIDS threatens above all the young and the healthy; that it
predominantly a sexually transmitted disease means that most of its dire
victims are aged 15–45, so that the indirect victims of this epidemic incluc
millions of children and other dependents of the formerly young an
healthy.

AIDS may be the first modern epidemic, in that its spread — and tl
medical/political response to it — are very much products of a glob
society, in possession of unparalleled, if poorly, distributed medic
scientific resources. The Canadian sociologist John O'Neill has identifie
AIDS as 'a potential globalizing panic on two fronts; namely (a) a crisis
legitimation at the level of global unisexual culture; and (b) a crisis
opportunity in the therapeutic apparatus of the welfare state and tl

sweeping generalizations, but he identifies some crucial elements of the epidemic. Thus, within a few years of the syndrome being identified in several American city hospitals, its cause, the human immunodeficiency virus (HIV), had been isolated, and the World Health Organization had established its Global Programme on AIDS (GPA) to coordinate an international response. No illness in human history has generated so many meetings, so many scientific publications, nor so much political rhetoric and government response.

There are many ways to understand AIDS as an epidemic of modernity: its spread and the social constructions attached to it are closely linked (in the poor world) to the dislocations of economic and social 'development' and (in the West) to the growth of particular sub-cultures and regimes of sexuality. The widespread acceptance that AIDS results from infection by a particular retrovirus (HIV) was only possible in a historical period in which the paradigms of western biomedicine are dominant; the stress on seeing it as 'sexually transmissible' rather than (as is the case for hepatitis) a 'preventable communicable disease' owed a great deal to the ways in which AIDS was first identified and depicted. The spread of HIV through most of the world, and the growing epidemic of HIV/AIDS in poorer countries, above all in Africa and South Asia, generally regarded as the most 'under-developed' regions of the world, has been hastened by such features of globalization as 'the erosion of traditional community-based social interaction and institutional mediation of meaning, and their replacement by marketplace institutions, structured wage-labor and . . . the "industrialisation of culture"'.[2] Moreover, it has been accompanied by a reinforcement of western-derived scientific techniques — epidemiology; surveillance; blood-testing; behavioral interventions — which further strengthen the assumptions of modernity. Thus, ironically, many of the techniques of the modern (i.e. Western) world are mobilized to fight an epidemic whose spread owes a great deal to other aspects of western intervention in much of the world.

AIDS, as O'Neill stresses, meant a crisis for the 'world disease system', for it was not susceptible to management by existing state/medical apparatuses, which were galvanized into a variety of responses ranging from repression and restriction, to partnership with previously ignored and stigmatized groups. Most striking of all has been the response from those most affected by the epidemic itself. Very soon after the first newspaper stories began to appear in the United States (in 1981) telling of a new and mysterious condition which was afflicting young gay men, the gay community began to organize in response. Gay Men's

Health Crisis in New York (GMHC) became the first of a whole series gay-based organizations which were to spring up across the world, r only in cities in North America, Europe and Australia, but in developi countries such as Mexico, Zambia and Thailand. As the disease began be isolated in frightening numbers in Central and East Africa, grou based on the affected communities came together to build organizatio such as The AIDS Service Organization (TASO) in Uganda, whi shared with the gay-based groups of the developed world a commitment community-based responses to the threats of the epidemic.

No other illness has enlisted such a variety of skills and communit to organize against it. In countries ranging from Kenya to Thailand to t Dominican Republic, sex workers have developed programs to educ and support fellow prostitutes and their clients. In the tolerant cit of Switzerland and The Netherlands, but also in the urban ghettoes Newark and Camden in the USA, communities have sought to restr infection amongst needle users, whilst in India and Russia and Argentir against horrendous obstruction and persecution, people with the vir themselves have struggled to organize against discrimination a ignorance.

Although I am concerned to talk of what is common to t community response in both the industrialized and the non-industrializ world, it would be silly to ignore the real differences which exist. It see likely that during the 1990s there will be a greater and greater gap betwe two AIDS epidemics, that in the rich world and that in the poor worl The crucial distinction is not one of epidemiology, as was suggested early WHO conceptualizations of Patterns I, II and III, but rather political economy, both as it applies to the availability of treatments and vulnerability to infection. In the rich world, advances in drug therap make it increasingly possible that HIV infection is on the way to becomi a 'manageable condition' akin to, say, diabetes, and that medi advances will mean more people infected are able to live longer and bet lives after diagnosis. Even if one remains pessimistic about su developments, medical treatments can at least prolong life and relieve considerable amount of the suffering caused by opportunistic infectio These developments are largely meaningless in most of the poor worl where the resources required for care with new drugs are unimaginable. most cases the spread of the virus will be closely correlated to econon conditions, as poverty not only makes effective education and t provision of condoms and clean needles more difficult, but also it oft deprives people of the choice to make use of these even if they a available.

countries will be able to buy the new treatments, and the very poor in rich countries will miss out. This seems true for many people of colour in the United States identified by some analysts as a 'fourth world'. Within South Africa, as in the United States (and perhaps Brazil), the two epidemics co-exist within one country. (Some minority populations within US cities are now experiencing the reality of three generations of HIV infection within one family, a phenomenon far more akin to that in the developing world than that found in middle-class America). Maybe the development of a cheap vaccine, effective both as prevention and as therapy, will alter the situation. But it is hard to escape the reality that HIV/AIDS will become increasingly yet another arena which reproduces already existing dimensions of inequality.

There is one way in which strange similarities exist, and that is in the language of warfare which surrounds so much of the rhetoric on AIDS. 'Fighting', 'combatting', 'battlefield' are all terms which surface continually, and not only in western bio-medical or activist language. Consider, for example, this description of an Indian medical-based AIDS organization:

> 'This is not "his" or "her" problem. It is my problem and your problem, and it is only if we work concertedly together, hand in hand, sharing experiences, problems and solutions, that we have some chance of winning the war — and win it we must!' states Dr. Suniti Solomon, tired but happy after a long and fulfilling day in the battlefield.
>
> Dr. Suniti Solomon, Dr. Ganapathy and others of the AIDS Resources Group at Madras Medical College are always willing to render every help and assistance, impart any information, knowledge and experience in their power, to anyone willing to sign up as a soldier in the cause of AIDS awareness.[3]

There are strange echoes of this rhetoric back in the heart of the empire, where one researcher said: 'It's a war-type coalition where everyone gets their jackets off and mucks in.'[4] The attraction of such language may say something about the dominance of military metaphors; maybe in using this language we can signal both the urgency of the issue and the centrality of biomedicine (with its imagery of the invasion of the body by hostile germs) in responding to it.[5]

This book grows out of both an intellectual and a political commitment to the idea that without strong community-based responses

the best meaning of public health systems will fail to deal with the crisis of AIDS. Unfortunately in most countries the public health systems are very far from being even minimally adequate, as much as from lack of political will and prejudice as from lack of resources. One of the major goals of the community-based movement has been to slowly drag public officials to a recognition of the multi-faceted needs of an appropriate HIV/AIDS strategy. As Steven Epstein wrote of the United States: 'It is the gay community that has invented and disseminated the idea of "safe sex" trained hundreds of volunteers to staff information hotlines, set up local AIDS libraries, used direct action to challenge the Food and Drug Administration's slowness to make available experimental drugs, held forums on varieties of alternative treatment.'[6] How much greater is this need in developing countries, which lack the governmental infrastructure which for all its clear weaknesses does exist in the United States.

This book grows directly out of my own experiences and is equally limited by them. When the first reports of the new disease appeared, I was living in New York City, although I cannot claim to have been particularly quick to grasp the importance of what was being reported. My first contact with the new disease was to attend a fund-raising tea dance for the newly formed Gay Men's Health Crisis. Several months later I toured the country promoting my book *The Homosexualization of America* and I recall no questions at all being asked about what was then beginning to be referred to as GRID (Gay Related Immune Deficiency). The next year, however, I taught in the spring at the University of California, Santa Cruz, and I remember reading a *Time* cover story together with a small group of gay men that made it clear that an epidemic had begun, and that it would impact profoundly on our lives. Later that year I was approached to write a book on AIDS, which became *AIDS in the Mind of America* (published in Britain as *AIDS and the New Puritanism*).

As I struggled, as did all gay men at that time, with the fears of the unknown that came with our awareness of a disease for which no known cause or cure yet existed, I also struggled to understand it as a writer trying to get a handle on the ways in which small groups of people, largely but by no means exclusively gay, were coming to terms with the new challenge. I remember early conversations with bewildered and frightened doctors; I also remember my panic when, in a hotel bathroom in Honolulu, I thought I found a purple lump on my foot. As part of my research I attended a number of early AIDS Conferences, including the first International one in Atlanta in 1985, and others in San Francisco New York, London, and Montreal. Early in 1985, the then Australian Health Minister, Neal Blewett, visited San Francisco and I spent a few

important once I returned to Australia.

I moved to Melbourne midway through that year, and took a position at a local University. Gradually, I became more and more involved in the AIDS world, both in Australia and internationally. These various involvements will inevitably colour this book, which is the work of an academic gay man based in Australia, and with a far greater knowledge of the situation in North America and South-east Asia than in Africa or South America. I have often written directly out of my own firsthand knowledge, but the strengths of this approach bring with it the countervailing weakness that other equally important experiences are ignored. That is why I quote so frequently from as diverse a variety of sources as were available to me: I would like to think that many voices speak in this book, though I hope in chorus rather than cacophony. (Because so much of the information I have been able to gather is ephemeral and often based on one person's observations, some of it may inevitably be incorrect or out of date. Please accept in advance my apologies for any such pieces of misinformation.)

Over the years I have visited a large number of community-based organizations, in buildings ranging from modernized high tech office blocks to renovated shacks on the streets of urban slums. One image remains with me, and that is of movement: AIDS community organizations seem to be constantly outgrowing their space, to be shifting premises as the load on them and the resources available increase (though the latter never as fast as the former). Packing crates and not yet connected telephones seen as good a symbol as any of the energy and the stress which characterises the communal response to the AIDS epidemic.

This book began as one on 'community-based organizations and AIDS', but I quickly realized it needed to deal with both the impact of and community responses to AIDS, of which the organizational was a significant part but by no means the total story. The extent to which the epidemic has involved mobilization among those people most affected is remarkable and worth the attention of all those interested in political activism and social movements. The epidemic has produced an extraordinary amount of creativity, political activity and compassionate care at a grass roots level in virtually every country where there exist the possibility of communal organizing. There are many players in the response to HIV/AIDS, and often doctors, researchers and government officials seem to be taking the lead. Yet without the daily work of hundreds

community effort, the impact of the epidemic would be considerably more devastating.

Talking of community-based organizations (CBOs) involves certain assumptions about the concept of 'community', which in turn will have very different meanings depending on the epidemiology of HIV in different societies. In countries where AIDS is largely confined to particular groups, or where certain groups have been significantly stigmatized because of the threat of AIDS (often the case for sex workers and homosexual men), it is fairly clear that a CBO is one which grows out of and retains a link to that group. (The development of AIDS organizations often plays a significant role in building a sense of community amongst stigmatized groups, as we shall see.) In other countries, particularly in Africa and the Caribbean, the affected community is far less discrete, and a community base may mean only that the organization grows out of a popular base and retains some form of representivity. Certainly any idea of 'community based' must involve some sense that the organization represents the community in question, and how this is done is one of the major theoretical problems facing almost all AIDS CBOs.

The term 'community' is one of the most complex and imprecise in the vocabulary of social science. The term is usually applied to a group of people defined by certain boundaries, such as race, ethnicity, religion or profession — the American community, for example, or the chiropractic community. In a press release issued for World AIDS Day 1992, whose theme was 'AIDS: A Community Commitment', the Director General of the World Health Organization, Dr Nakajima, defined 'community' in very narrow and apolitical ways: 'The community — be it neighbourhood, the school or the college community, a professional group or the smaller support network composed of family and friends — is a uniquely powerful force in societies everywhere'.[7] Not only does this description of 'community' seem badly out of step with the groups WHO had itself been supporting for some years, but it barely touches on those concepts of 'community' around which people are inspired to organize. Often place is the crucial variable, and community is defined in geographical terms: indeed, many of the central works in 'community studies' assume a geographical base to 'community'.[8] Others have given it a spiritual meaning, as in M. Scott Peck's assertion that 'We must restrict it [community] to a group of individuals who have learned how to communicate honestly with each other, whose relationships go deeper than their masks of composure, and who have developed some significant

other, make others' conditions our own'.[9]

A moment's thought will show that the term can be so all-embracing as to be largely useless (as when politicians invoke 'the Australian community' or reference is made to 'the heterosexual community') but it can also be reduced to very small segments: within 'the Australian community' one might speak of 'the Catholic community', then 'the Polish Catholic community', then the 'Sydney Polish Catholic community', then the 'teenage community of Sydney's Polish Catholics', then 'the stamp collecting community of Sydney's Polish Catholic teenagers' and so on, *reductio ad absurdum*. For different purposes all these categories may well form self-defining communities, that is groups of people who feel enough in common for whatever reason to share common aspirations, goals and institutions. (In *Habits of the Heart*, a study of modern America, Bellah *et al.* define community as 'a group of people who are socially interdependent, who participate together in discussion and decision-making, and who share certain practices that both define the community and are nurtured by it'.[10]) Community, it should be noted, is a term applied both to groups whose membership is determined by birth (e.g. ethnic communities) or choice (e.g. professional or interest-based communities) or perhaps a mixture of the two (e.g. religious affiliation).

Many people identify, of course, with more than one community, and this poses particular issues for people of minority ethnic, racial or religious status who are also homosexual. Does an ethnic Punjabi living in Britain who is homosexual see her or his primary identification with the South Asian or with the gay community? How does her or his sense of identity change if s/he is HIV positive or an injecting drug user or a sex worker? As the epidemic has grown, a number of community-based organizations have emerged which try to provide space for people whose dual — or multiple — affiliations could cut them off from single community organizations. Thus in the United States there are a range of ethnic AIDS organizations; in Britain the Naz Project, an HIV project for 'the South Asian and Muslim community' seeks both to provide space for acceptance of people with HIV in those communities, and also to make other agencies aware of the special concerns of South Asians and Muslims. Hostility towards and ignorance of homosexuality in many minority ethnic communities has led in turn to specific minority gay AIDS groups, which seek to act as bridges between 'mainstream' gay and ethnic organizations.

For the sake of consistency I have chosen to stick with the imprecise term 'community based organization' because it seems to me the best short hand form of encompassing a number of seemingly different

(This point is discussed further in the next chapter.) The very strength o the term 'community' lies in its reference to both ascriptive and voluntar association: there are echoes of the sense of family, of sisterhood/fratern ity, which is more powerful than the more limited concept of 'voluntar association' or 'AIDS service organization'. The phrase used by novelis Sarah Schulman — 'the community of mourning friends'[11] — touches o some of the realities of the epidemic for groups as diverse as New Yor queers and African villagers. More importantly, the term 'community based organization' carries with it overtones of political representation an empowerment which 'AIDS service organization' does not: communit control is one of the issues focused on within this book. As a report on th health requirements of Australian Aborigines recommended:

> Community control is the local community having control of issues that directly affect their community.
>
> Implicit in [this] definition is the clear statement that Aboriginal (and Islander) people must determine and control the pace, shape and manner of change and decision-making at the local, regional, state and national levels.[12]

There are other 'community organizations' involved in the AID story who do not, by and large, appear in this book, and those are th various right-wing groups, both religious and political, who have use HIV/AIDS to further their agenda, whether this be a 'return to traditiona morality', or, as in the case of Jean le Pen's National Front in France, t support the case against immigration. Such groups have many of th characteristics of community-based organizations, and are often ver effective in mobilizing support and lobbying governments. In the Unite States, groups such as Americans for a Sound AIDS Policy wer influential in pressuring the Centers for Disease Control to be ver cautious in their approach to prevention programs.[13] Because such group rarely include those most affected by the epidemic I shall refer to them a part of the larger political environment facing the community sector i AIDS, although in some cases they might demand inclusion in that secto itself. This is seen in the case of the French group Adipos, made up of HI positive ex-drug users, which preaches abstinence from drugs and fough bitterly against its exclusion from an international NGO AID Conference in 1990 in Paris. At the 1993 International AIDS Conferenc in Berlin, considerable protest surrounded the appearance of the Swis group Aids-Aufklarung (AIDS Information), whose opponents claimed i

workers and drug users, and for mandatory testing of these groups.

Several terms and influences on my view of the world need to perhaps be briefly explained at this point. Some of the literature which deals with community responses to AIDS, particularly that which comes from Latin America, places considerable stress on the concept of civil society, and the need to strengthen it. This concept, which I also find immensely useful, is derived from the work of the Italian Marxist Antonio Gramsci, who distinguished between 'civil' and 'political' society 'where the latter term refers to the coercive elements within the wider social totality, the former to the non-coercive'.[14] It is not surprising that this distinction is particularly attractive to analysts of societies which have known authoritarian governments (Gramsci after all formulated his theories while in a Fascist prison). It becomes very significant in explaining the weakness of the non-government sector in many parts of the world where organizing around AIDS means simultaneously challenging the dominance of the state. Yet even in those countries where civil society is strong, conventional political analysis pays remarkably little attention to voluntary and community organizations, even though for many people this is the arena where they are most likely to feel some sense of empowerment.[15]

The other major theoretical concept which I shall use is that of agency, meaning a belief that humans largely constitute their own nature, culture and history, and hence can consciously choose to alter structures of inequality and subordination which are often seen as inherent and unchangeable. Those familiar with certain current intellectual debates will recognize that I am firmly positioning myself on the side of what is sometimes derided as 'humanist materialism'. While the stress in this book is mainly on organizations, I am sufficiently influenced by Gramsci to recognize the importance of 'intellectuals' in the largest sense in helping communities make sense of the meanings of AIDS. Hence the emphasis on cultural responses, in both the aesthetic and anthropological sense of that word.

All the AIDS organizations with which I have had contact have been nurtured (to borrow a term of Bellah's) by their close connection to communities which are deeply touched by the HIV epidemic. Because of this closeness there is both a certain strength and a potential subversiveness to their work. AIDS requires community mobilization: for care of those infected, for effective education to prevent the spread of the

virus, or to work against discrimination and persecution, and it is becau[se] of this that AIDS demands many of the features associated wi[th] community development. In turn, real 'development' requires wh[at] David Korten has termed 'social learning':

> Social learning cannot be mandated by the pre-emptive action of central political authority. Nor can it be programmed by bureaucratic procedures. It is a product of people, acting individually and in voluntary association with others, guided by their individual critical consciousness and recognizing no organizational boundaries. Its organizational forms are found in coalitions and networks, which become aggregated in larger social movements, driven by ideas and shared values more than by formal structures.[16]

Real 'development' — development, that is, which is centred on t[he] perceived needs of communities rather than the agendas of econom[ic] growth as laid down by the International Monetary Fund and the Wor[ld] Bank — is inherently subversive. It is particularly subversive when, with AIDS, it requires the recognition and empowerment of people w[ho] are often marginalized — sex workers, gay men, injecting drug users an[d] more broadly, women, children and the poor. Above all the search empower those with AIDS themselves becomes, as we shall see, subversi[ve] of some of the most dominant discourses of power in the modern worl[d] those based on medical and scientific authority and expertise.

No one can hope to have a full overview of AIDS organizations; o[ne] estimate in 1992 suggested there were 16 000 non-governmental groups the United States alone doing some HIV/AIDS work. Certain theme[s] however, run through this book which go beyond the immediate descriptive: I shall be speaking in different ways of empowerment, community, of legitimacy, of representation, of expertise. These terr[ms] betray my background as a political scientist — even though th[e] discipline has hardly distinguished itself by analyses of the epidemic and reveal yet again the very political nature of the epidemic. In the fir[st] analysis, the stories I am telling are stories of human beings comi[ng] together to understand, respond to and manage the devastation caused [by] what many now see as the first modern plague. 'The challenges of AIDS as the Director of the Global Programme on AIDS, Michael Merson, p[ut] it, 'are increasingly the challenges posed by other afflictions of mode[rn] society . . . AIDS is like a beacon, pointing up our weaknesses and helpi[ng] us chart the best way forward.'[17]

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3 Rajan, R. P. (1992) *Pragnya: From Consciousness to Awareness*, Madras, AIDS Resource Group of Madras Medical College, p. 17.
4 Quoted by Berridge, V. and Strong, P. (1992) 'AIDS Policies in the United Kingdom' in Fee, E. and Fox, D. (Eds) *AIDS: The Making of a Chronic Disease*, Santa Cruz, University of California, p. 309.
5 See the discussion of language in Davies, P.M., Hickson, F., Hunt, A., Weatherburn, P. and Project Sigma (1993) *Sex, Gay Men and AIDS*, London, Falmer Press, pp. 39–40.
6 Epstein, S. (1988) 'The Gay Community and the Experts', Paper delivered at the Homosexual Identity During, Before and After HIV Conference, Stockholm, June, pp. 13–14.
7 Press Release, WHO/19, March 27, 1992.
8 There is a contemporary version of this tradition in Boyte, H. (1984) *Community is Possible*, New York, Harper.
9 Peck, M. S. (1988) *The Different Drum*, London, Rider, p. 59.
10 Bellah, R. *et al.* (1988) *Habits of the Heart*, London, Hutchinson, p. 333.
11 Schulman, S. (1991) *People in Trouble*, New York, p. 99.
12 Quoted from 'A National Aboriginal Health Strategy' (March 1989) in Consultation Paper #1, Report of the Working Panel on Aboriginals, Torres Straight Islanders and HIV/AIDS DCSH, Canberra (May 1989).
13 See Bull, C. (1993) 'The Silence of the Labs', *The Advocate*, Los Angeles, January 12, pp. 50–4.
14 Milner, A. (1993) *Cultural Materialisms*, Melbourne, University Press, p. 54.
15 Michael Walzer has argued that this lack of interest is changing. See his 'Between nation and world', *The Economist*, September 11–17, 1993, pp. 45–8.
16 Korten, D. (1986) 'Community Management and Social Transformation' in Korten, D. (Ed.) *Community Management: Asian Experience and Perspectives*, West Hartford, Kumarian Press, p. 325.
17 'Revamp Medical Education says WHO AIDS Programme Director', Press Release WHO/63, August 10, 1993.

Chapter 2

The Emergence of a Non-Government Response to AIDS

A number of factors will influence the course of an epidemic, of which th bio-medical are not necessarily the most important. In the case of HIV, i spread was largely related to specific social and cultural patterns: th sexual networks of homosexual men, the availability of needles, th political and economic power relationships of prostitution, the nature transport routes through areas of high prevalence. Just as the discovery the virus was only possible because of pre-existing knowledge an assumptions about (retro) viruses, so too the ways in which it spread, an the responses to it, were very much products of particular ideologica political, and social formations, present in the last decades of the twentiet century.

While there were clearly significant differences between the impact HIV in developed and developing countries, differences linked to th epidemiological patterns found in various societies, AIDS became a realit in a world where global communications had already broken down man of the traditional frontiers and differences between countries. It is perhap symbolic that the first AIDS cases diagnosed — though almost certainl not the first to exist — were found among homosexual men, for the ga world is a particularly international one, involving rapid mobility an cross-cultural contacts. Without accepting Randy Shilts' rather fancifu concept of 'Patient Zero', an airline steward who infected large number of homosexual men across North America,[1] there is little doubt that HI was spread rapidly via international travel, and the common explanatio for relatively high infection rates among homosexual men in places a dispersed as San Juan, Sydney and Zurich was their interaction during th early 1980s with American gay men.

developed world, beginning in North American gay ghettoes and moving from there into injecting drug user and hemophiliac populations, the other, far more generalized, beginning in Central Africa and spreading not into specific communities but into the 'general population'. While Africa was not necessarily the source — certainly not the only source — this latter pattern was repeated in the Caribbean, South and South-east Asia and the rest of Africa. This has some parallels to early mappings of the epidemic which spoke of Patterns I, II and II based on different epidemiological patterns. Just as these are too simple — in some parts of the world, e.g. Brazil, one could find evidence for all three patterns simultaneously — so too is a divide between the developed and the developing world in terms of the political and social response. Denial and the availability of resources for prevention, care and community organization is not always linked to levels of development or affluence: few societies have been as reluctant to come to terms with the challenge of AIDS as was that very rich country Japan. Community responses were often strongest in countries with relatively few resources, such as Uganda or Zambia.

Nor were social responses to HIV/AIDS necessarily that different across frontiers. Unfortunately denial, ignorance and persecution on the basis of AIDS has been almost universal, and the stigma of the disease has clearly been compounded by its association with already stigmatized forms of sexual (and drug-using) behavior. Almost all societies went through periods in which there were attempts at branding AIDS as a disease imported by foreigners, whether it was Japanese gay bars refusing admission to westerners, the banning of foreigners (in practice white foreigners) from prostitution complexes in Indonesia, or Indian doctors refusing to treat African students. (Typical of many reactions were the comments of one Indian state health minister that : 'There is a risk of foreigners giving us this disease called AIDS on a platter.'[2]) AIDS panics have taken different forms in different societies, but it would be foolhardy to assume they have been less frequent in societies with greater levels of education and affluence, and an increasingly globalizing media ensured that scare stories, and those portraying AIDS as a disease of 'the other', spread rapidly across the world.[3]

Just as the epidemiology of AIDS must be understood within its social context, so too must the community response. The decade in which AIDS was recognized, conceptualized and named was a decade in which the Western world was undergoing the economic rationalizations of Reagan and Thatcher. As Elizabeth Fee and Daniel Fox have written: 'Containing health costs had become a major objective of governments in the United

recognize, let alone deal with, the potentially devastating costs of coping with a new epidemic.'[4] These concerns were reflected in the 'structural adjustments' imposed on developing countries by international agencies led by the International Monetary Fund and World Bank which also meant severe reductions in the size of the public sector.

There is considerable literature on the impact of 'structural adjustment' on developing countries, and the ways in which it has both increased income gaps within many countries, hastened rapid migration to the shanty towns which now make up the majority of Third World metropolitan areas, and hit women particularly hard.[5] In a 1993 letter to the President of the World Bank, written by the Inter-Church Coalition on Africa, the 'single greatest factor' contributing to the poor health of the developing world was identified as the Bank's own emphasis on the diverting of resources to debt servicing and the development of export industries.[6] Moreover, AIDS developed in a world in which political upheavals, particularly in Eastern Europe and the former Soviet Union, would start to reshape the post-World War II map of the world, while destroying public services in places torn by civil strife such as Bosnia and Georgia.

Whether because of 'structural adjustments' in South America and Africa, the impact of civil strife and military rule in Burma and Cambodia, or the collapse of Communism in Eastern Europe, the spread of the epidemic has often been directly related to larger questions of political economy. One cannot understand, for example, the role of prostitution in Thailand, and the growing importation of young girls into Thai brothels from neighboring Burma and Laos, without understanding the inter-connected power of the military and certain government and business interests. The opening up of Vietnam and Cambodia to tourism and the subsequent development of a large sex industry have dramatically increased the risk of spreading HIV infection.[7] The war on drugs, whether in the 'golden triangle' of South-east Asia or in South America and US cities, has changed patterns of drug consumption, often increasing rather than decreasing needle use as against inhalation or smoking.

From the former Soviet empire of Eastern Europe and Central Asia come disquieting reports of the spread of HIV as basic services (including blood screening and the availability of disposable syringes) break down, as population mobility and commercial sex increases, and as there are no resources available for prevention or for basic information. As one writer put it: 'The Berlin Wall acted as the world's biggest condom'[8] since its collapse HIV has the potential to spread rapidly in Eastern Europe. In

shortage of syringes, and stringent Catholic restrictions on providing condoms. Many hospitals in the former Soviet Union lack facilities for proper sterilization, and HIV information is rarely available.[9]

I prefer a formulation which stresses the centrality of political economy to vulnerability to AIDS and its impacts to that which has been framed by Jonathan Mann and adopted by the Global AIDS Policy Coalition (of which I am a member: this is clearly a friendly disagreement over priorities). In a statement of the Coalition one sentence is central: 'The critical relationship between societal discrimination and vulnerability to HIV is the central insight gained from a decade of global work.'[10] But 'societal discrimination', whether due to difference of gender, class, race, nationality, sexuality or occupation, grows out of the political economy of a given society, namely those arrangements which determine the allocation of resources both nationally and internationally. In a number of cases 'development' itself contributes to the conditions making for vulnerability, as when economic changes force many out of rural life, pushing young men to leave their villages for the cities or minefields, and young women into urban factories or 'hospitality' work, disrupting families and increasing commercial sex.[11] Political economy, too, helps explain the ways in which AIDS research is both funded and directed. If, as is generally believed, about one third of all HIV/AIDS research is controlled by the pharmaceutical industry, it becomes important to note that this is essentially an industry dominated by large firms concentrated in half a dozen countries, with development and research led by the United States, Japan and a handful of Western European countries.[12]

If the epidemic developed in a world of structural adjustments and privatization, it also developed in a world in which feminism and gay assertion meant the existence, in at least some places, of existing organizations and communities able to respond to the new crisis. The very idea that community-based organizations should play a leading role in meeting the challenge of a public health crisis is related to a whole series of political and social developments over the past twenty years. The redefinition of public health, sometimes described by the term 'the new public health', achieved official status with the adoption in 1986 by an international conference of 38 countries of what has become known as the Ottawa Charter. This declaration is committed to a policy of 'health for all', stressing the importance of primary health care, of the promotion of healthy life styles and of prevention and health promotion. Most significant for our purposes, the Ottawa Charter, through its focus on the creation of supportive environments and the 'enabling' of communities

sense a challenge to professional practice as it is found throughout the world.'[13] As the Charter states: 'Health promotion works through concrete and effective community action in setting priorities, making decisions, planning strategies and implementing them to achieve better health. At the heart of this process is the empowerment of communities, their ownership and control of their own endeavours and destinies.'[14]

In a sense AIDS, already developing at the time the Ottawa Charter was adopted, proved an acid test for the principles of 'the new public health'. (It may also have showed the limits of this new paradigm, particularly in its failure to place respect for basic human rights in a sufficiently central position.) No other disease, Jonathan Mann has claimed, has so revolutionized attitudes to the meaning and provision of health care. The old paradigm, Mann notes:

> focused on discovering the external agents of disease, disability and premature death. Inevitably the emphasis was medical and technological, involving experts and engineers, and for certain purposes this approach was quite effective. However this paradigm envisioned a fundamental dichotomy between individual and social interests; accordingly, and in concert with the spirit of the age, governments were called upon to mediate and to prevent disease through laws and the work of bureaucracies. Attention to behavioral, social and societal considerations was often rudimentary and naive. Public health systems often favored coercion and compulsion without considering their effects on human rights.[15]

Already when AIDS was first conceptualized many of the assumptions of this old paradigm were being challenged. The requirements imposed by a new epidemic, which could not be cured nor prevented through bio-medical means, made new models of public health particularly relevant, as concepts of empowerment and self-esteem came to be central in the development of new strategies for education and intervention. Perhaps most significant, leaders like Mann developed an analysis of human rights as central to any AIDS strategy, not just for moral reasons but also because their abuse made it more difficult to reach and affect those people who were most vulnerable to HIV.[16]

Concern for human rights is a theme which runs through this book. For the moment let me note that there are two basic sorts of rights which have engaged community groups, namely those involving protection

support and care. The former have received considerable attention, with reference to issues such as travel, compulsory testing, confidentiality etc. The latter is less often discussed under the rubric of human rights, yet it is central: the greatest abuses of human dignity in the current epidemic are found in the extraordinary inequality of resources available to provide both basic information, preventive measures and even palliative care to those with HIV/AIDS. Access to condoms, to clean needles and to basic medical treatment is as essential to empowerment and self-esteem as is protection against discrimination and persecution, and larger concerns such as food and shelter have immediate consequences for HIV care and prevention.[17] All too often, access to such basic services is distorted by patterns of discrimination based on gender, race, sexuality and the larger inequalities of the global political economy.

The 'new public health' built on the interest in 'community organizing' that had been growing in most Western countries since the late 1960s (and become a major ingredient of development theory in many Third World countries). The new interest in 'community organizing' stemmed both from those with a commitment to grass-roots participation *and* from those interested in cutting back the role of the state, leading to sometimes strange alliances (in theory at least) between new right and new left critiques of the state. Particularly in the English-speaking industrialized world, cut-backs, economic rationalization and 'de-institutionalization' have been the framework within which conservative governments have seen community organizations as worthy of support. As Rosamund Thorpe suggests, governments have fostered community organizations as an alternative to more costly direct interventions, while at the same time such organizations develop from the anger of those who find the existing state system is unable to meet their demands.[18] While there may seem to be a division between those who see the voluntary sector as complementary to government, and those who see it as posing a fundamental challenge, by the early 1980s considerable numbers of people had been exposed to the ideas of participatory involvement, community organizing, opposition to large scale bureaucracy, and the need to transform political consciousness as a means of transforming social structures.[19]

For somewhat different reasons the idea of 'community development' was also enthusiastically fostered by various United Nations programs from the 1960s onwards, as a 'third way' towards economic development. As J. A. Ponsioen wrote in 1962: 'Community development is not only a method of development . . . The ideology of community development

approach — and the individualistic way through competition for material welfare — as was the Western approach. The ideology of community development appeals to the citizens of a community to develop their own initiatives.'[20] The influence of concepts of community development would become increasingly significant as international development agencies, both inter-governmental and private, became increasingly concerned with HIV/AIDS from the late 1980s on.

The stress on development would be accompanied by a somewhat belated recognition of the significance of gender, as there came to be a greater understanding of the double impact of HIV on women as both those at greater risk of infection and those on whom the burdens of care most heavily falls. In many developing countries, governments and development agencies have turned to women's organizations in order to develop AIDS-specific programs. But a feminist analysis had already impacted on the response to HIV in the developed world. As Eve K. Sedgwick wrote: 'Feminist perspectives on medicine and health care issues, on civil disobedience, and on the politics of class and race as well as of sexuality have been centrally enabling for the recent waves of AIDS activism. What this activism returns to the lesbians involved in it may include a more richly pluralized range of imaginings of lines of gender and sexual identification.'[21]

The Development of AIDS Community Organizations

As AIDS was first identified in the United States (where for a short time, let us remember, it bore the name Gay Related Immune Deficiency) it was here that the first community-based responses emerged. I have written elsewhere about the particularly American nature of volunteerism which was expressed in those early groups.[22] The first of them, the Gay Men's Health Crisis (GMHC) was formed by a group of concerned gay men in New York in 1982, and focused originally on research and education. Quickly GMHC found itself having to set up a plethora of direct services for people infected by the virus, and developed a large number of volunteers programs to help people in need of home care and support. One observer, commenting on the rapid development of GMHC into a major agency, quotes Tocqueville's admiration at 'the extreme skill with which the inhabitants of the United States succeed in proposing a common objective for the exertions of a great many men and inducing them voluntarily to pursue it.'[23] Those who volunteered for AIDS work,

American volunteers, particularly in health care, a group described by Diane Johnson in her novel of hospital life as 'a corps of candy-stripers and retired people of the upper middle class.'[24] As we shall see, they included a large number of people who were politically aware, and would demand a role in managing the epidemic very different from that of the conventional health-care volunteer.

This development of voluntary organizations providing direct services was soon followed in other American cities, then by comparable organizations in Canada, Australia and northern Europe, often directly inspired by the American model. The New Zealand case, where the original AIDS Support Network was founded by a small group of gay men, including one who had been infected by HIV during his time in the States,[25] was common to a number of countries. In Britain, the Terrence Higgins Trust was founded in 1982 by Higgins' lover and friends after he died of AIDS.[26] In Sweden and Denmark, the existing gay organizations became the central focus for HIV work in their communities, although there have been tensions between RFSL, the major Swedish gay organization, and the far more respectable Noah's Ark, which was established to do AIDS prevention and support in conjunction with the Swedish Red Cross. In a number of cases, such as the Netherlands and Canada's first AIDS organization, AIDS Vancouver, gay doctors played a crucial role. Indeed gay doctors, whether as individuals or through organizations such as the Bay Area Physicians for Human Rights in San Francisco, were critical as mediators between emerging community organizations and bio-medical and health authorities, although their role has tended to decline as the organizations have institutionalized their relations with the state. Similarly, the impetus for HIV organizing in some societies has come from nurses, as in Poland where one of Eastern Europe's first AIDS counselling services uses midwifery and nursing students for peer education.[27]

In all of these cases, such organizations could not have existed without the previous decade of organizing among gay men and lesbians which followed the student riots of 1968 in France and other Western countries, and the Stonewall riots in New York in 1969. During the 1970s, there had been a slow institutionalization of the new lesbian/gay consciousness which grew out of these political movements, with the development of a well-organized press, of social and political groups and of a large and visible commercial world.[28] Almost without exception the first AIDS organizations built on this base, and one observer has commented that in Germany 'the basic and leading decisions in health politics of how

were decided mainly in the triangle of state-medical system-gay movement.'[29]

Particularly important in these formative years was the gay press, which provided much of the available early information on the epidemic, as well as acting as a vital tool in mobilizing the community. When I lived in San Francisco for a while in 1985, non-gay researchers and educators found the *New York Native* (a gay bi-weekly) an invaluable source of information and ideas; the *Native* became far less influential as it became obsessed with a series of rather strange theories about the cause of the epidemic, but other gay publications, such as *Outrage* (in Australia), *Body Politic* (in Canada) and *Le Gai Pied* (in France)[30] seemed to provide the best explanations for non-specialists of what was painstakingly being reported in the medical press. A handful of gay journalists, such as Nathan Fain, Larry Mass, and Michael Helquist (in the United States) and Adam Carr (in Australia), played an absolutely crucial role in developing the base upon which early communal organizing could take place. Nor has the crucial role of the press been confined to the developed world: in India and Indonesia (and I suspect in some Latin American countries as well) the emergence of a gay press was an integral part of the development of early community HIV work.[31]

Where an organized gay base was lacking it was much more difficult to establish AIDS organizations. Apart from people with hemophilia, who also had pre-existing networks and organizations, other groups in Western countries found responding to the demands of AIDS much more problematic, so that even now there are weak communal structures in countries such as Spain and Italy where the epidemic is primarily found amongst drug users and their partners. (But even there the gay community was significant. Thus the first community-based organization in Italy, the Associazione Solidieta AIDS of Milan, was founded by gay activists, and the Portuguese group ABRACO has a significant gay membership amongst its Trustees.) While AIDS has gradually opened up space for organization among users, only the Netherlands, with its National Federation of Junkie Unions, had an existing institutional base for work among needle users.[32] Japan stands out as the one country where hemophilia organizations have been the most effective part of the community sector in influencing governmental responses,[33] although a number of other countries have provision for compensating people with hemophilia who contracted HIV through infected blood products.[34]

One study in the United States suggested that government responses to AIDS were clearly linked to the strength of the gay movement in

and non-government responses in most Western countries, and the failure to analyse the relationship between existing gay/lesbian organization and government responses is a weakness of the attempt by Moerkerk to develop a typology of European responses to the epidemic.[36] It is clear, however, that those countries he identifies as making a 'pragmatic' response to HIV/AIDS (The Netherlands, Norway, Denmark, and Switzerland) are ones where the gay movement was already institutionalized and recognized to a greater extent than those (such as Sweden, Germany, and Britain) where the response is described as 'political', and certainly more so than those where it is typified as 'bio-medical' (France, Belgium, Spain, and Italy) or emergent (Eastern Europe). In the latter two cases, the gay movement was weak or non-existent; in the case of the 'political response', governments sometimes seemed, as in the case of Sweden, interested in deliberately de-homosexualizing AIDS.[37] At least some areas of what was then West Germany and perhaps Belgium would seem to fit better Moerkerk's idea of the pragmatic, as in both countries there was considerable cooperation between the state and community groups. (It is also true that in Bavaria there was a more traditional public health response summed up by one commentator as 'contain-and-control'.[38]) The French case is also more complex: it is true that the gay community was far less organized than its Scandinavian or Dutch counterparts, but when Daniel Defert sought to establish AIDES in 1984 he was able to draw on very considerable gay support and personnel. Moerkerk's typology does seem to fit Britain, bearing out the observation of Simon Watney that gay communities were not recognized there as legitimate constituencies as in the United States, Denmark and The Netherlands.[39]

There was a further common element to those countries where AIDS organizations first developed, and that was a tradition of volunteerism. The willingness of citizens to participate in voluntary work is a particular feature of English-speaking democracies, and is nowhere more marked than in the United States. (Ironically, the emergence of groups such as GMHC and AIDS Project Los Angeles during Reagan's Presidency, caused some embarrassment for an Administration which loudly trumpeted its support for volunteer organizations — while being very unwilling to recognize that the gay community was taking the lead, as when it rejected a nomination of Gay Men's Health Crisis for an award honoring volunteer work.[40]) This tradition is much weaker in most other countries, and is often advanced as a reason for the slowness of AIDS organizations to emerge in countries such as France, despite their

that there was no tradition of volunteering because it was felt that the state should provide, and that volunteer service was 'women's work'.[41]

Despite this comment, the local branches of Deutsche AIDS Hilfe have, in fact, recruited a considerable number of volunteers. In France, and even more so in the rest of southern Europe, community-based organizations seem much weaker than in countries such as Canada or Australia, with smaller populations and lesser case loads. Nonetheless, by 1990 AIDES, which is by far the largest French group, claimed 1500 volunteers in 31 cities, and performed most of the services associated with AIDS organizations in English-speaking countries. It may be that just as France borrowed enthusiastically from American styles of homosexuality in the 1970s and 1980s, so it has been exposed through the AIDS epidemic to American style volunteerism.

It would be a mistake to assume that volunteerism is confined to developed Western countries; some very poor countries have a strong tradition of both community organizing and volunteer work. Some African countries have a rich network of local community groups, and groups such as TASO in Uganda, or the Family Health Trust of Zambia, have an extensive volunteer component. AIDS workers from India have told me that contrary to my expectations they could call on a large number of potential volunteers, mainly retired people and students. (In some cases volunteers receive what one organizer referred to in conversation as 'incentives' for their work, a recognition that one must have a certain basic standard of resources to be able to 'volunteer' anything.) The Duang Prateep Foundation, which operates among slum dwellers in the docks area of Bangkok, is able to draw on a network of mainly student volunteers for a range of education and community services.[42] But it is true that the initiative for many of the groups which are emerging in developing countries clearly come from people who are rather similar in background and commitment to those who founded the first AIDS organizations in the West, and in some cases — for example middle class Westernized gay men, or professional women working with street kids in places like Brazil, the Philippines, or India — are divided by large gulfs of class, culture, and even language from many of the people with whom they seek to work.

Certainly the epidemiology of AIDS was different in most of the developing world: not only in Africa, but also in most of the Caribbean, parts of South America, and in South Asia. The early AIDS organizations in these parts of the world, however, also grew out of existing networks and organizations, and in South America in particular the gay influence was very significant.[43] In countries as dissimilar as Peru, Mexico and

specific groups (and at least in Nicaragua and Peru lesbians played a central role). In Chile the first HIV organization, the Corporacion Chilena de Prevención del SIDA, was begun by a group of gay men, and in turn gave rise to a specifically gay group which then broke with the Corporación. In Brazil some gay groups joined with social workers, researchers, liberal clergy, and PWAs (People with AIDS) themselves to establish HIV/AIDS organizations.[44] In Malaysia and Singapore, gay men played a crucial role in the first AIDS organizations, and in Malaysia it was the defiantly named Pink Triangle which has become the country's best known AIDS group. Gay networks were important in the beginnings of AIDS organizing in India, Hong Kong, Japan, Indonesia and the Philippines (where one of the first gay groups took its name from the bar where its members first met to become the Library Foundation). The development of AIDS groups in Eastern Europe and the former Soviet Union appear closely linked to the emergence of gay organizations.[45]

In Africa there was some gay influence, for example through the early support for community-based work in Zimbabwe and South Africa, but there the main push came from those most affected by the new epidemic, usually women, who bore the double burden of direct infection and the responsibility of caring for others. Uganda's first AIDS service organization, The AIDS Support Organization (TASO) was founded by Noreine Kaleeba in 1987 after her husband had died from AIDS, and in its origins brought together people who were themselves infected, or who were living with people who were infected. In South Africa, a black woman activist, Refiloe Serote, was instrumental in the establishment of the Soweto Townships AIDS Project and Alexandra AIDS Action.

In other cases, already existing organizations, whether religious, social or developmental, became the major focus for grass roots AIDS work. This was true, for example, in some parts of Africa and the Pacific where the Red Cross or church groups such as the Salvation Army established AIDS projects. It was equally true in Thailand, the Philippines, and India where existing non-government agencies, some of them already involved in grass roots and community development work, became the focal point for much HIV work. (In both India and the Philippines existing health organizations often took on HIV work, and the Indian community sector is notable for the extent to which organizations are still dominated by doctors.) In some countries it was international NGOs such as the Red Cross which provided the basis for initial AIDS organizing, and which continue to provide the bulk of funding and personnel.

The two major variables in the establishment of AIDS organizations

extent to which the disease was concentrated in, and identified with, particular groups, and the extent to which such groups had the ability to develop their own organizations. By the latter, I am referring to existing traditions of organizing outside government, to the amount of space available for community mobilization. One would not be surprised to find virtually no AIDS organizations in countries such as China or Iraq where the private sphere is virtually non-existent; equally it is not surprising that they are stronger in Sweden than in Romania, in Nigeria rather than Zaire, not because the incidence of AIDS is higher in the former (it is not) but because there is a much more developed tradition of community organizing, and more acceptance of its role by governments.

While it is often assumed that community organizations are most likely to occur in rich industrialized countries, in fact the political system rather than economic affluence seems a more reliable guide to the possibilities for organization. Some countries of Asia and South America have traditions of grassroots and community work, stronger than can be found in some much richer countries of southern Europe. Equally, the prospects for community-based groups seem particularly weak in the countries of the Middle East, where governments even in rich countries such as Saudi Arabia or the Gulf states are particularly inhospitable to them.

In some of those countries with limited political space for political or communal organizing of the western sort, there is nonetheless a strong basis for community mobilization and education through the institutions of the state or the dominant political party. In a number of developing countries, 'mass organizations', often of women, youth, students, etc., are the closest structures to community-based organization, and in some cases they have been mobilized to run AIDS prevention campaigns. Their dependence on governments does, of course, raise questions about their ability to reach people engaging in activities which are officially denied or frowned upon, but in both Vietnam and China there are signs that some far-sighted officials have found ways of stretching the limits of what is allowed in the interests of prevention. (In China, for example, there has been a limited amount of outreach to homosexual men in Beijing which involved some tentative attempts at community building, at least until it went beyond what the government could accept.)

In the early developments around AIDS one can see the outlines of a struggle for control, in which medical professionals, government officials, affected communities, and traditional sources of moral authority, particularly churches, vied to be seen as the 'experts' on the new disease.

bitter struggle: was it to be understood as a primarily bio-medical problem, in which case its control should be under that of the medical establishment, or was it rather, as most community-based groups argued, a social and political issue, which required a much greater variety of expertise.

At some level the ways in which an epidemic is conceptualized determines the sort of responses which are possible. If for example it is seen as essentially a foreign import, then screening and quarantine become attractive measures: the Indian minister referred to earlier went on to argue: 'This country is not so supine as to just sit and watch . . . At least we should screen the high-risk group among foreigners, because our women are exposed to them.'[46] If, on the other hand, it is understood as the result of private behavior among people, many of whom will have good reason to fear state regulation and control, there is likely to be a very different emphasis on education and grass-roots organization.

This point can be illustrated by the sort of comparison already referred to by Moerkerk between the response of countries such as The Netherlands and Norway, which tended to the latter response, and those (also liberal democracies) such as Sweden and Belgium where there was a much stronger emphasis on traditional public health methods of control. Within the United States there are striking differences between cities such as San Francisco, where a pre-existing gay/lesbian political establishment affected the city response, and more conservative jurisdictions such as Miami or Dallas. Here the human rights dimension becomes crucial: in almost all countries, as we shall see, discrimination and prejudice has made the defense of basic human rights a central issue for AIDS organizations. The extent to which this is supported by governments is a reflection of larger political forces and pre-existing political patterns.

The role of CBOs has been increasingly supported by international agencies, such as the Global Programme on AIDS (GPA) and the United Nations Development Programme (UNDP). They have produced copious documentation arguing for the centrality of the community sector in meeting the challenges of the epidemic, and in providing peer education and on-the-ground support and care. They have been less forthright about the need for CBOs to play a role in policy making, although without this being recognized the community sector runs the risk of becoming a source of cheap labor carrying out programs which may not be appropriate to the needs of those it represents.

Governments tend to speak of non-government organizations (NGOs) and community-based organizations (CBOs) without making much distinction. The former term is a much broader one, and one which covers both the sort of grassroots response to AIDS found in GMHC, Pink Triangle, or TASO, as well as the established international agencies such as Red Cross, World Vision, or the Salvation Army. In an early attempt at clarifying these terms Broadhead and O'Malley wrote of: 'groups which represent the views of and act on behalf of their own members: peasant movements, trade unions, and feminist organizations, for example. Such bodies are referred to as 'people's organizations' to distinguish them from those NGOs which act as intermediaries in the development process rather than as grassroots organizers.'[47]

How we conceptualize AIDS organizations — which terms we use — is therefore crucial. For the most part this book speaks of 'community-based organizations' (CBOs) rather than 'non-government organizations' (NGOs) or 'AIDS service organizations' (ASOs). The former is, of course, a much broader grouping, which could be discussed in terms of the work of, say, the Red Cross and Red Crescent, or of already existing development agencies (Oxfam, World Vision etc.) in the HIV field. Many NGOs are international, and it is often difficult to distinguish between the work done as a result of external decisions and that which is driven by indigenous factors. (Using a broad definition of NGOs one estimate claimed that by 1991 there were more than 200 NGOs working on AIDS in Africa and 500 in Latin America.[48]) ASOs is a term used by the World Health Organization's Global Programme on AIDS, and is useful to describe all those organizations other than government which provide services related to HIV. At the same time it implies an emphasis on the provision of efficient services but not necessarily on accountability or representation. In recent years there has been some use of the term GOGs (Groups Outside Government) and, in the United States, PVOs (Private Voluntary Organizations).

With all these terms the emphasis is clearly on groups which are independent of the state and whose membership is by choice rather than ascriptive. If we exclude economic associations, and those which are not controlled by their membership, we further refine the concept to mean 'spare time participatory associations', which is the approach adopted by David Sills.[49] A further refinement is to use the term 'self-help organization', and Carl Milofsky has recently proposed the term 'community self-help organization', to center on groups which 'represent

resource mobilization, and building a sense of community and of geographic identification.'[50] The term in much social work literature of self-help groups places the emphasis on the people who are affected, but has connotations of limited and non-political activity, while voluntary organization has similar drawbacks — the emphasis suggests people who offer to assist within existing structures rather than to create forms which allow them to determine their own work. Nonetheless, at least one major national AIDS organization — Deutsche AIDS Hilfe — refers to itself as a self-help group (at least in its English publications), and defines itself as an amalgam of a professional association and a representative body.

A further refinement of this idea comes in the distinction made by Aggleton, Weeks and Taylor-Laybourn between self-help and altruism as competing characteristics of AIDS organizations.[52] There is already a small literature around the concept of 'altruism' in AIDS work, with some disagreement about its centrality. While Weeks and Kayal, writing of Britain and the United States respectively, have seen it as a very significant concept, Patton is more critical, stressing the need to 'deconstruct the revitalized rhetoric of altruism which reappears in the context of Reaganism after nearly two decades in which new social movements have reached community and self-empowerment. This new, rightist altruism has engendered social policies . . . [of] privatization of formerly social welfare practices. This maneuver relies on free market economics that presuppose notions of individualism and competition, an implicit evolutionism which undercuts analyses of systemic disenfranchisement of racial/ethnic minorities, and in the late 1980s equated volunteerism with female leisure activity.[53] Some of this difference, as Weeks points out, is due to the greater strength of a social democratic notion of the state in Britain than in the United States; there is a religious component to Kayal's notions of altruism which is very American in its conception. While Patton's warning seems to me important, it is also true that the amount of volunteer work in AIDS organizations is remarkable, and no less so because there is a complex mix of motivations underlying volunteer involvement.[54]

In general I shall use the term 'community-based organization', which is the term adopted by those AIDS organizations with which I am most familiar (although there are some language problems: outside Quebec the term 'organization communitaire' has little meaning in French). Certainly the elements which Milofsky seeks in his 'community self-help organization' are those I will seek to elucidate in the discussion of community-based organizations — except that the rather clinical term

devastation which the HIV/AIDS epidemic represents to those who ar responding to it. In using the term community-based organizations recognize that this may leave open just which and whose communities ar being referred to, and that many of the groups I shall discuss work with rather than grow organically out of, their communities. For my purpose the basic test is the extent to which the organization has a commitment t the development and the empowerment of the people it claims to represen (and thus some groups may be included which in other senses are mor accurately described as NGOs).

Other non-government organizations have developed in response t AIDS, both fund-raising bodies, such as the American Foundation fo AIDS Research (AMFAR) or the Japanese AIDS Foundation, an associations of professionals such as the AIDS Society for Asia and th Pacific (ASAP), but these would not normally fit the definition of a CBO On the other hand we shall be discussing some organizations which di not originate because of HIV, but which have accepted AIDS as one o their central concerns. The clearest example may be the variou organizations of people with hemophilia, but there are many othe examples, such as the development agency ENDA (Environmenta Development Action in the Third World) based in Senegal which list action against AIDS as one of its 10 major development priorities.

It should be noted that in most cases there will be a strong emphasi on volunteerism in these organizations, even if the bulk of work i performed by paid staff. Writing of Indonesia Philip Eldridge has mad the point that;

> most organizations could not function without paid staff, even though general levels of remuneration in the voluntary sector are generally below what can commonly be obtained in the public or private sectors, with longer and more unpredictable working hours. However, the other dimension of meaning associated with the concept of voluntarism, emphasizing autonomy, free will and creativity remains important to the whole enterprise.[55]

Eldridge suggests implicitly that community organizations exist in third sector, which is neither that of the state nor of profit-drive enterprise, and this distinction is significant in both developed an developing countries.

Rather than dividing organizations between those in the develope and the developing world — which is an unnecessarily crude an

divided between those which are based in communities defined by behavior and those defined by place. The first case includes groups based on identities which are assumed to have a special relationship to HIV/AIDS: people with hemophilia, gay men, injecting drug users, sex workers, street kids. The second involves the more traditional usage of community as related to geography, and will be found where HIV is spread more widely through a particular area without it being particularly linked to any minority behavior or identity. Such places will be found largely in the developing world, although there are some community organizations in ethnic ghetto areas of the United States which would fit this model.

There are further permutations one might suggest: some organizations, such as TASO, were founded by and include many people who are HIV positive and their families.[56] In many cases existing organizations became *de facto* AIDS organizations, whether these were hemophilia societies, church groups in parts of Africa and the Pacific, or development agencies such as ENDA. This is true for a number of groups working with sex workers, where organizations such as Empower in Thailand or Kabalikat, a health and welfare agency in the Philippines (whose full name means 'partner of the Filipino family'), found themselves increasingly involved with AIDS, partly because of the magnitude of the problem and partly because of the availability of HIV-related funding. As HIV impacts more and more on women, one can see an increase in the role of women's organizations in the HIV field. In India many of the small NGOs working on HIV/AIDS grew out of already existing networks of primary health care organizations.[57]

Though useful for analytical purposes, the distinction between AIDS-specific and more general organizations is often blurred. In many cases HIV has been the trigger for community organizing among previously unacknowledged communities, whether these be sex workers, drug users, or gay men (sometimes in alliance with lesbians), and these organizations in turn will develop new forms of community and will make new demands on the political system. The development of gay organizations in a number of Asian cities in the past few years has clearly been assisted by the AIDS epidemic, which has generated both a sense of urgency and some resources for organizing.[58] AIDS is often the impetus for organization among sex workers, as in the case of the group Patita Uddhar Sabha which was set up in 1992 by prostitutes in Delhi's red light area to demand better health facilities and the supply of condoms.[59] Even organizations of positive people are rarely totally exclusive, often allowing participation for lovers, family and friends, giving rise to the phrase 'people living with AIDS' (PLWAs).

Thinking about community immediately opens up very interesting w
of extending the now well-known distinction between behavior
identity. We are used to recognizing that by no means all men who h
sex with men can be thought of as members of the gay communit
would suggest that equally there are some people who do not have sex v
their own gender who may well be part of that community: their wc
their commitment, their political allegiance binds them to it, even if t
would fail a Kinsey scale test on sexual orientation. Such people h
played a crucial role in almost every gay-based AIDS organization
has an unresolved contradiction between the fact that they claim a spe
relationship to the gay (sometimes gay and lesbian) community, while
providing support and services to everyone affected by HIV, irrespec
of sexuality.

In the case of other communities of identity there are somew
different issues. Many people who speak for sex workers or drug users
not so themselves (though they may once have been). Where prostitu
and drug use are heavily stigmatized and criminalized it may indeec
impossible to develop communal organizations; the best one can do i
develop advocacy organizations which will seek to represent th
(Sometimes professional social workers claim to speak on behalf of d
users and sex workers, though in effect retaining a traditi
professional–client relationship.) Effective user groups still ren
essentially confined to a small number of liberal social democracies, s
as The Netherlands, Germany, Australia, and Italy, although there
small amount of peer-based outreach to drug users in Malaysia, Ne
Thailand, and Brazil. There is a parallel in some developing countr
where the gay presence in AIDS organizations needs to be played do
so that a group such as Action for AIDS in Singapore is *de facto* a
organization, but because very few people are prepared to come out as
must disguise this to some extent.

Whether sex workers and users will generate communities simila
the gay community seems to me an open question. Unless there
willingness to assert that sex work and drug use are actually desirable
difficult to see how they can become the basis for a genuine socio-poli
identity: so far the bulk of self-organization has tended to hover une
between an apologetic and a defiant tone, which is not sufficien
produce the basis for a communal identity. Thus a declaration of
European Interest Group of Drug Users in 1992 proclaimed: 'As
alcohol, we do not encourage drug use. But if a person uses drugs

medical and social care, safer use and harm reduction.' This is not the language of self-assertion usually associated with successful community organizing.

Yet despite this reservation, it is certainly true that community organizing by and among commercial sex workers has been a feature of HIV/AIDS work in large numbers of countries, often following a model described for Morocco:

> Our point of entry was 'Fatima', a prostitute with whom we developed a relationship at our clinic in Casablanca. We gave her condoms to distribute to her colleagues, and some of them began coming to us with her in search of information about AIDS. This led to the creation of peer education networks which distributed condoms along with information about AIDS and other sexually transmitted diseases. Fatima and several of her fellow prostitutes have made an audio tape in which they speak in their own words about AIDS prevention.[60]

Even though the organization among sex workers in this case originated with an existing agency, the encouragement to the women to develop their own networks and their own means of education, without any pressure to remove them from the sex trade, makes this approach fall clearly within the ambit of community development.

Unlike the more traditional community organization based on place, the development of identity-based CBOs is closely related to larger questions around sexuality (or, in the case of users, drugs). But even the geographic-village, neighborhood-community organization dealing with HIV will find it comes in contact with similar issues. Any attempt at grass roots prevention education means confronting the realities of human behavior which propriety and custom would prefer to ignore. Prostitution, child abuse, homosexuality, and drug use are realities that those working in AIDS constantly face, and in dealing with these realities more conservative community organizations themselves go through cultural and social changes. At the grass roots level many church groups accept, and even encourage, practices such as the use of condoms that their leadership proscribe. At least one Catholic organization in Brazil, Apoio Religioso Contra AIDS, has supported the self-organization of commercial sex workers.

A dialectic process is at work here: communities give rise to organizations, but organizations can also help create communities as

around categories such as sexuality, sex work, and drug use. Indeed, th extent to which the early discourse around the epidemic stressed its links t homosexuality ('the gay plague' was a common term in many countries — even though this was soon not an accurate reflection of the know epidemiology — helped ensure a powerful mobilization in response. Ther is a certain irony that an epidemic that in some ways has brought a upsurge of homophobia (in its original meaning of 'fear and loathing o homosexuality and homosexuals') has also led to the strengthening of ga communities and the recognition of homosexuality as legitimate in man parts of the world.[61] At least in some countries the same is true for dru users and sex workers.

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Chapter 3

What Do CBOs Do?

The obvious retort to the question in the title of this chapter is, of course, 'Everything': there is virtually no aspect of HIV-related work in which there is not involvement by one community group or another. CBOs are involved in research, in providing direct medical services, in palliative care, in helping frame government policies, in addition to their more common role as providers of education, support and advocacy to those infected or affected by HIV. As Michel Pollak wrote of the situation in France:

> The voluntary sector . . . represents a combination of the different features of a self-help group of the sick, a pressure group in favor of more research funds, and an expert group intervening in public debate. They are at the same time an avant-garde for launching new ideas for the health sector and a public force that the health institutions can use to increase broad support for more resources and reform measures.[1]

Nonetheless, the bulk of the work of CBOs in the epidemic revolves around two major concerns: support for those already infected and preventive education (largely, but not entirely, for those who are not infected). To meet these two goals requires not just the provision of services, but constant advocacy and interaction with governments, health providers and potential donors. The balance between these areas will change as the nature of the epidemic changes, and each encompasses a very wide range of activities.

For several years a friend of mine worked as a volunteer 'buddy' with Gay Men's Health Crisis. As a buddy he regularly visited his 'client' — who in one case became a close friend — assisted with housework, shopping, medical visits. Most important, he became a lay counsellor, someone in whom his client could both confide and trust. Buddies may seem artificial, people who take the place of family and friends in a society too anomic to ensure that people can count on a personal support system in time of need. (One GMHC board member described them 'as people who would act, towards strangers, as ethically they would act towards friends'.[2]) But in fact the buddy develops a unique relationship with his client, one which supplements but does not replace that of lovers, family and friends. However close s/he becomes, there is still the advantage that it is a relationship shaped by the particular needs of illness, and this allows a certain freedom in the relationship which cannot exist with those already part of the client's family. Because the buddy does not expect friendship to be reciprocated, the client has licence to express far more of her or his anxieties than is possible with others; because the buddy comes from another world s/he is able to offer a different kind of support.

The complexity of services needed by people with AIDS meant that the original concept of buddy was supplemented by other workers, who specialized in client advocacy, namely assisting people to work through the various bureaucratic tangles involved in getting services from different layers of government. The essential component of the program remained that of the volunteer working directly with someone who was sick; as one GMHC volunteer wrote:

> GMHC actually trains volunteers very very well not to think of themselves as miracle workers or anything more than what they are . . . It was really mostly just about presence. Witnessing. Listening. Hearing people's stories. Being human. Not just being Florence Nightingale and beaming patiently at bedside while someone blabs on and on. Sometimes it was about bringing some flavor or excitement from the outside world into the room, to stir up the air a little bit.
>
> The two major clients I had, whom I stayed involved with over a period of months couldn't have been more different. Tony was a teacher of deaf kids, a witty (even bitchy) queen, formerly a cute young thing, who complained incessantly about his family and friends . . . Alfredo was a twentysomething illiterate Latino was impossible to have the kind of conversation you and I would have over cappuccino. It was always depressing and sometimes scary to go to visit him in his roach-infested, outrageously overpriced welfare-hotel room. But he was always extremely grateful for every little bit of attention or help he got.[3]

Little wonder that the idea of the buddy soon was adopted by other AIDS organizations in other countries, even though the failure of volunteers to keep up with the growth in case loads has meant that GMHC has had to cut back on its own buddy program.

Early on in the development of community-based AIDS groups, the desire to provide direct assistance to those who were sick and dying proved one of the main reasons for the entry of most volunteers into AIDS groups. Indeed, for many 'volunteering' came to be synonymous with caring for someone who was sick, and many AIDS organizations developed large scale home care and support services which are a model for community-based care for other diseases. Two American organizations established programs that were soon studied and emulated by groups from other western countries: Gay Men's Health Crisis, which pioneered the buddy system, and Shanti in San Francisco, an already existing project for the terminally ill which developed a range of volunteer counselling and support services for People with AIDS. (By 1990, when San Francisco had recorded over 7000 AIDS cases, Shanti was operating its own hospice.) In Britain, London Lighthouse was developed to provide 'a place of safety' for people with AIDS offering a full range of residential, day and home care services. Its building in Ladbroke Grove is the major centre for positive people in greater London, offering a continuing range of services including meals, complementary therapies and counselling to something like 1500 people each week,[4] and while there has been some criticism that it is not equally available to all those with HIV/AIDS, it is, as Richard Davenport-Hines has written, 'a marvellous institution that provides an innovatory and flexible model of health care.[5] Day-care centres exist in some American and Australian cities, and in Stockholm, and full residential care is provided by the Bailey-Boushay house in Seattle.

Support services cover a gamut of areas, ranging from the immediate and obvious needs of counselling those who are newly diagnosed and providing home care once they become sick, to more specialized services such as looking after the pets of those who are too sick to care for them any longer (e.g. New York's Pet Owners With AIDS Resource Service, POWARS), or working with prisoners, as is done in France by the Groupe

new needs in areas such as legal and financial advice, housing, etc. One of the larger AIDS organizations in France since the late 1980s is APARTS (Association pour les Appartements de Relais Therapeutique et Social) which seeks to provide housing for People With AIDS. No AIDS organization to my knowledge operates a hospital, although ABRACO in Lisbon comes close through very extensive links with the state Hospital de Egas Moniz.

What united these diverse services was a sense that AIDS both hits people who cannot rely on traditional sources of emotional, physical and financial help, and that there was a need to develop community-based and voluntary services for those who are affected. At one end of the spectrum this can lead to the traditional paternalistic sort of charity work, which Dominique Lapierre describes unwittingly in his praise of Mother Teresa's efforts to care for People with AIDS (PWA) in both India and New York.[6] At the other, support becomes support for the empowerment of People With AIDS to take control of as many aspects of their situation as possible, and the growth of a PWA movement, which will be discussed later in this chapter.

In most Western countries, support and care groups originated within the gay community, and this remains true today: as one example, the Finnish gay group, SETA, has helped develop support services across the country for non-gay clients. But even where, as in Australia and parts of North America and northern Europe, those needing care are predominantly homosexual, there has been a striking influx of non-homosexuals into support programs as volunteers; the volunteers who run home-care programs in my home city of Melbourne are drawn from a wide range of people, including large numbers of middle-aged married women. Even though issues of cultural sensitivity surface from time to time — Christian volunteers who are uncomfortable with male lovers; drug users who feel hostility towards their gay carers — AIDS has produced a quite remarkable coalition of carers, united by a basic human concern to look after those who are sick and dying. This brings to mind the distinction made by Aggleton, Weeks and Taylor-Laybourn between 'altruism' and 'self-help',[7] although I am concerned that this may suggest a greater dichotomy than in fact exists: there are elements of altruism in the commitment of many of those who are themselves directly affected, just as apparently disinterested service is a form of self-help for many apparently altruistic volunteers.

Many of those involved in AIDS work have found it becomes almost literally the focal point of their life, and this is true for comparatively large

one woman in Melbourne, a married woman with four children, came into the AIDS Council as a volunteer from an Orthodox Jewish background that was so strict that she would not switch lights on or off during the Sabbath; for her, involvement in AIDS work led her, via immersement in the gay bar scene, into experimenting with her own sexuality and leaving AIDS activities to live with a female lover. Involvement in AIDS work clearly met a large number of personal needs which have little to do with the altruism she clearly displayed in her work as a support volunteer.

As the epidemic spread, care came to be required for the survivors as well as those who are themselves infected, above all for the millions of children orphaned by AIDS.[8] There are a growing number of community-based organizations which seek to work directly with families, both infected and survivors, some of them founded by mothers with AIDS themselves, such as the Ugandan Women's Efforts to Save Orphans (UWESO)[9] and the AIDS Widow, Orphan and Family Support, also in Uganda.[10] Care and support for orphans is a major goal of the Family Health Trust of Zambia, which is committed to 'rehabilitation through empowerment and participation'. Sometimes there may seem to be tensions between providing services for those who are sick and/or infected, and offering support to those who are HIV-negative but nonetheless affected. As AIDS organizations have proliferated, groups have sprung up to cater for lovers, spouses, parents, children, siblings, workmates etc. of those with HIV, as well as for larger categories such as HIV-negative gay men.

In countries with inadequate health systems, community organizations may be the only place where basic medical treatments can be found. A graphic example comes from Tijuana, on the Mexican-US border, where the AIDS group ACOSIDA (Alianza Contra el SIDA) established an HIV clinic which makes drugs available to AIDS patients with assistance from activists in neighboring San Diego.[11] Similarly, HIV groups in countries such as Chile and Malaysia have arranged with Western counterparts to import drugs such as the anti-viral AZT and acyclovir (for herpes). In some African countries there have been imaginative programs to link hospital-based care and home care, as in Zambia where a hospital provided huts in the hospital grounds for families of those in hospital to make it possible for them to take part in care-giving The Chikankata project seeks to incorporate family members into al stages of the caring process, and to use this as a basis for expanding knowledge of HIV and decreasing the stigma attached to the syndrome

CBO) and one might question the emphasis in the programs on Christianity and promoting 'chastity before marriage and mutual faithfulness within marriage, either in monogamous or polygamous relationships'.[12]

Even in the absence of hospital beds and drugs — and Tijuana, for all its problems, is clearly in a privileged geographic position — home care is becoming a growing demand on community organizations in many developing countries. Indeed, developing appropriate models for care is one of the most immediate demands for community organizations in much of the developing world, where outside Southern and Eastern Africa, the focus to date has been very much on prevention. Imaginative use of existing community and cultural resources will be required, as in some tentative moves which have been made to make use of monastries in Thailand as a base for home care within villages.

The dominant discourse on AIDS is inevitably Western, and essentially determined by governments, donors and international agencies who accept the priorities of Western medicine. Because of this, it is easy to forget the importance of traditional healers and health-belief systems in many countries where HIV presents itself. A summary of a workshop on traditional healing in Southern Africa pointed out that even in Zimbabwe, one of the richer African countries, the vast majority of people looked to traditional healers, and while some examples were cited of traditional healers and doctors cooperating (in Lesotho) or of traditional healers (also in Zimbabwe) saying that they cannot cure AIDS, this is balanced by other examples, such as that from Zambia where 'some traditional practitioners have been propagating the thought that "white people" can't cure AIDS'.[13] I am not concerned here to argue the benefits or otherwise of traditional medicine, only to point to the reality that, first, it is a resource for many people and, second, that the hope that practitioners of Western and traditional medicine can work together does not always allow for the real disputes over power and expertise that are involved. There are potentially very large tensions for AIDS organizations who may need to juggle the traditional beliefs of their clientele with the implicit acceptance of Western models that comes with external funding and support. TASO, for example, has associated itself with the use of Western-style medical care, and warns against some of the practices of traditional healers[14] although many TASO members make use of traditional medicines, and there have been some attempts to develop cooperation between traditional and Western-style healers.

Although I am dealing with care and education under separate

in developing countries particularly have noted that caring for someone with AIDS becomes a very strong motive for behavior change. In some ways, testing for HIV becomes the focus of a link between prevention and care: although this is probably a declining view, many programs have encouraged widespread testing as part of a general prevention and information strategy, while those who test positive immediately move into a new category — the person with HIV — for whom care, support and counselling is required (though usually not available). Significant numbers of community organizations offer testing and counselling services, promising a protection which may not be available at government or private test sites:

> At Action for AIDS [Singapore] Anonymous Counselling & HIV Testing, we try to make a difficult process a little easier. What makes us different from other clinics is: We don't want to know who you are . . .
>
> The anonymity of a number. The full respect for a human being. Give it a try.[15]

Testing, as will be argued later, raises complex issues around human rights and allocation of resources. The provision of confidential testing and counselling services combines elements of education, care and advocacy, and can be important in creating community awareness of the issues surrounding HIV. This is suggested by the experience of WATCH (Women Acting Together For Change) in Kathmandu, who seek to link HIV prevention to larger questions of empowerment and organising amongst Nepalese women.[16]

Prevention and Education

Unlike the provision of support, at least in its more traditional forms, th development of community-based education programs tends to lea almost inexorably to political action, even if this is not recognized as such As a pamphlet (in English) of the French group AIDES put it: 'One alon cannot change his or her behavior: a social movement and opinion leader are needed.'[17]

From the beginning of the epidemic effective education — as distin from the provision of basic information — was largely the work community-based organizations. Government departments can (thoug

ments, public service announcements on radio and television etc. They are far less likely to be able to reach people directly in ways which will change behavior rather than merely increase abstract knowledge.

A decade into the epidemic we are well aware that many people know how HIV is transmitted without necessarily acting on this knowledge to protect themselves from infection. (In some cases those who are infected also may not act to prevent transmission of the virus to others.) What is required is deceptively simple: protected intercourse (i.e. with condoms) and clean needles for injection. The obstacles to such measures being adopted universally are enormous, and involve ignorance, denial, cultural and religious resistance, unavailability of condoms, clean needles and/or bleach, and in some cases willingness to take risks which may be rational (for example, for those who need to prostitute themselves to survive and thus lack the power to bargain with clients). In most countries one can see a common trajectory, as the provision of basic information, through brochures, posters and telephone counselling, becomes supplemented with more intensive community-based activities. There is sometimes a parallel development of what is called 'social marketing', namely the use of the profit motive to increase use of condoms. While this approach can increase both health awareness and availability of condoms, it is doubtful if by itself it can persuade people to change their behavior.[18]

This trajectory owes a great deal to the work of gay groups, which essentially invented the idea of 'safe sex' and developed methods for making it part of the norms of the gay community that other groups and communities are now seeking to emulate. Simon Watney traces the idea of safe sex to the 1983 pamphlet by Michael Callen and Richard Berkowitz, *How To Have Sex in an Epidemic*, which was written even before HIV had been isolated.[19] In fact even earlier pamphlets were produced by both the Sisters of Perpetual Indulgence (an order of gay male nuns) in San Francisco and the KS/AIDS Foundation in Houston.[20] What is striking is that before a theory of community-based education had been articulated by AIDS workers, groups in the gay community were setting its practices into place.

An enormous variety of methods have been used by CBOs in doing AIDS education. These range from conventional provision of printed materials and posters through public speaking, telephone counselling services and safe sex demonstrations to focused peer education. Telephone counselling, for example, is a common activity in both developed and developing countries, and is sometimes linked with other education work as in the case of the Remedios Foundation in the Philippines. But the

range of education and information activities is enormous: one publication, picked at random from a pile of materials sitting on my study floor, described formal training for health officials by the Family Planning Association of Sri Lanka; school debates in Hong Kong; sex education workshops in the Marshall Islands; and a theatre performance in the Pacific island state of Vanuatu:

> The Wan Smolbag Theatre, Vanuatu's first full time community theatre company, has now produced an AIDS education play with the title 'The Warm Night'. It is about three men — a Ni-Vanuatu student in Australia; a Ni-Vanuatu working on a fishing vessel that calls regularly at Bangkok; and a philandering expatriate now working in Vanuatu after many years in Africa. The play highlights several possible ways in which AIDS and HIV might be introduced to Vanuatu.[21]

Note that these examples are largely drawn from the work of non-AIDS specific groups (and in the latter case one which seemed determined to paint AIDS as coming from overseas, a justified assumption in Vanuatu at that stage). Peer education however is possible only where the affected communities themselves produce education efforts. And peer education takes many forms. In Swaziland, for example, a program called the Man Talk Project uses men to reach out to other men to encourage the use of condoms. As one report said, 'the NGO hopes to create awareness throughout the country of its logo and to associate it with strong male images.'[22] In Toronto, the Canadian Organization for the Rights of Prostitutes (CORP) founded a Safe Sex Corps to do outreach work to both female and male sex workers. In Thailand, dancer Natee Teerarajjapongs founded a dance troupe in 1987 that used a combination of traditional dance and agitprop theatre to put across safe sex messages to bar workers in the Patpong area of Bangkok. His group became the basis for work among non-commercial gay men in Thailand through the organization FACT and now runs a drop-in center in Bangkok, as well as seeking to educate men in parks, saunas and other places of sexual contact.[23] In France direct peer education for gay men was done through a 'Jack-Off Club', organized by Santé et Plaisir Gai, which used group sex parties to promote both the knowledge and practice of safe sex. Gay outreach in Singapore by a group of men based in Action for AIDS includes use of sketches, drag shows, quizzes and prizes to reach otherwise apathetic or resistant men.

Peer education rests upon certain assumptions about the need to

groups as far apart as EMPOWER in Thailand, sex-worker groups in Brazil, and the Australian AIDS Councils have deliberately linked the notion of peer education to community development. In the case of EMPOWER (which stands for Education Means Protection of Women Engaged in Recreation), an organization working among sex workers in the commercial heart of Bangkok, much of their stress is on teaching bar girls skills (such as English) which can increase both self-esteem and their ability to better protect themselves in the workplace. But empowerment involves communal as much as individual projects, such as the *Patpong* newspaper, which one (undated) brochure described as: 'a means for people, hitherto without a voice, to communicate their ideas and express their opinions. A sense of pride is generated in being involved in a collective project newspaper, a sense of pride that says *Patpong* is for me, about me and by me.'[24] (EMPOWER has grown beyond its Bangkok base, and now has branches in several provincial centers.)

Similar work is being undertaken by sex-worker groups in Australia, the Dominican Republic, Mexico, The Netherlands and the United States among others.[25] In Brazil, the Rio de Janeiro Prostitutes Association (APERJ) has established links between women working in the Vila Mimoza red light district and hospital and family planning services.[26] APERJ provides health information, condoms and support against both police and private harrassment, and works with a local community radio station to increase health awareness. Yet, as one study revealed, most of the workers cannot afford to buy condoms, and the number available to the organization cannot meet the demand.[27] This is a not uncommon problem for grassroots community organizations, who speak bitterly of the waste and corruption in many national AIDS programs. In Bombay, volunteer workers for the Indian Health Organization and Population Services International befriend and advise sex workers, but must battle not just poverty and ignorance but also the corruption of the sex trade and the willful disinterest of much of the health system.[28]

There is clearly a lot in common here between the work of EMPOWER and APERJ and the approaches used by Western gay groups in their approach to community building. There are parallels, too, in some of the work done by youth groups and groups of indigenous peoples, such as young Native Americans for whom effective HIV education raises much broader questions of oppression and self-esteem.[29] Peer education is usually discussed for its efficacy in HIV prevention, but it also plays a crucial role in community building. Reflecting on their experience of education in Singapore, members of Action for AIDS have spoken of the

decriminalization of homosexuality in Singapore.[30] When Alfred Machela established a gay program within the Township AIDS Project in Soweto he was forced immediately to confront both the homophobia and racism of South African society.[31] (As part of that project a volunteer group, the Gay People's Health Forum, does specific community development work among lesbians and gay men.) Groups such as Pink Triangle in Kuala Lumpur, Bombay Dost in India, Proyecto Germinal in Lima and the Library Foundation in the Philippines have explicitly linked the development of peer education for homosexual men with the growth of a gay community, and used the space provided by HIV programs to do both. (In some cases this has spread to support for lesbians; by 1993 Pink Triangle was offering women's only social meetings in its offices.) As the Manager of the Victorian AIDS Council Education Program wrote:

> One man in Melbourne, whose only previous contact with the gay community was via the beats, is now, following involvement in the Peer Education program, convening a Project Team in Melbourne to educate other beat users: an outstanding example of movement along the community development continuum, and an example which clearly links this model to effective AIDS prevention programs.[32]

One of the most vexed questions for gay-based AIDS education projects has been whether and how far to make them relevant to lesbians; considerable energy has been spent on debates about the stake of lesbians in the epidemic, and, in particular, the extent to which they might be seen as at risk of HIV infection. (At the 1992 International AIDS Conference in Amsterdam there was a noisy protest aimed at the Terrence Higgins Trust which was seen as unsympathetic to the danger to and needs of lesbians.) On the one hand, many gay men have argued that lesbians are at risk largely through shared needles or sexual intercourse with infected men, and hence specific information for lesbians is misleading and unnecessary. Against that, at least one strand of lesbian analysis has insisted that they are being neglected as a reflection of the more general invisibility of lesbians:

> Lesbians are therefore *under-represented*. We are there but we are denied voice and face; our collaboration in this process of invisibility is obtained through the continual identification of sex between women as unnatural, a threat, not-sex or non-existent.

lesbians who are (for instance) [illegible]
their sexuality in order to protect themselves from further abuse.
Being a lesbian is therefore a cultural struggle to break through
silence and invisibility: we have ourselves only as battering-rams.
For many of us being out is a high risk activity. Measure that
against the public profile of gay men.[33]

The debate around HIV services for lesbians reflects the larger problems of defining AIDS around *behavior* as against *identity*. Most HIV-positive women who identify as lesbians were infected by activities that were behaviorally not homosexual, but to say this does not mean that their sense of identity is not very different from that of women, infected through similar behavior, who define themselves as heterosexual. In particular, some of the social stigma experienced by homosexuals of both sexes is presumably a factor in increasing the risks to lesbians of infection, if in somewhat different ways than is true for male homosexuals.

In the same way, education programs among sex workers quickly led to demands for better conditions and self-respect that becomes subversive of existing gender and commercial structures. Romantic illusions aside, sex workers are usually drawn from the poorest and least well educated sectors of society. Speaking of the Indian situation Sundararaman, a Madras doctor who has worked in the streets with sex workers, points out that most sex workers are illiterate, ignorant of many basic health issues and without power or resources.[34] To create a situation where sex workers can demand that their clients use condoms with some chance that this will succeed requires the transformation of both self-images and political relationships. In most developing countries sex-worker groups are likely to be established by middle-class individuals and agencies who provide some resources (education and health materials, drop-in centers, training etc.), which in turn provides possibilities for at least a few sex workers to speak for themselves.

The more politically radical will see empowering sex workers as their prime goal: thus Talikala, an organization working with sex workers in Davao, in the southern Philippines, encourages the women to organize, and trains them to do outreach AIDS education. The women who founded Talikala were concerned from the outset to both understand and empower the women with whom they worked, and had a strong understanding of the fact that health education could only be meaningful within the context of a broader community development perspective. While the Filipino government has been generally supportive of this work, Talikala has been

[illegible] ganization came from the Maryknoll Fathers.

Equally, peer education programs amongst drug users almost anywhere will take on a political dimension, as the very act of declaring oneself part of a 'user community' helps undermine the assumption that users are sick, criminal and/or irresponsible. Even in countries where there has been a certain amount of official support for 'user groups', there has been a great deal of confusion (and sometimes hypocrisy) about the nature of these groups, and particularly the role of current users. (User groups generally include both past and present users, with an understandable reluctance on the part of those who are currently taking illegal drugs to declare themselves.) In one article in an official WHO publication it was conceded that: 'Generally "the government" is seen by drug injectors as only being interested in stopping drug use and there is scepticism about the sincerity of any official efforts to prevent the spread of HIV among injecting drug users.'[35] There is a clear contradiction between one arm of government promoting (and funding) 'user groups', while another continues to persecute anyone suspected of using.

Nor should we overestimate the ability for 'self-organization' among users; the great majority of them are almost certainly outside the reach of community organizations or peer outreach programs, and likely to be dealt with brutally. This is not surprising in American ghettos or Indian towns (where there is a major concentration of users in the northeast states bordering 'the golden triangle'),[36] yet even in Germany, often thought of as one of the more socially progressive of countries, one analysis spoke of drug users as 'entirely unrepresented and unorganized . . . a miserable life lived in the shadow of illegality, where only the meanest and fittest can survive even temporarily'.[37] A more measured study in the United States pointed to the difficulties, both societal and cultural, which face users' organizations.[38] Its solution, which is to suggest the leadership role of ex-users invoking the model of Alcoholics Anonymous moves away from the more radical self-assertion of those groups (e.g. the Dutch Junkiebonds) which have sought to organize without abandoning drug use. On balance I am inclined to accept the judgement of Friedman, de Jong and Wodak that user groups have proved 'far more successful than many would have considered possible a few years ago'.[39]

Even where peer education does not become explicitly political, there is always the need to make certain clear choices about the sort of messages to adopt, in particular whether to push for abstinence (fewer sexual partners, no more drug use) or safety (as in the example of Santé et Plaisir Gai above). A survey for the book *AIDS in the World* covering 25 major

countries promoted sexual abstinence, this is the goal of a small minority in developing countries[40] where both religious influences and a pessimism about the use of condoms has sometimes led to support for messages of monogamy as in Uganda where this position was supported by both church and President.[41] The problem with this message, as Marvellous Mhloyi has pointed out, is that it targets women who are already monogamous, but whose husbands are not, and unlikely to change because of economic, cultural, and social factors.[42]

Where the education efforts have been led by gay or sex worker groups they have tended to adopt a more sex-positive — some would say realistic — attitude, stressing that safe sex need not mean less sex. This in turn becomes reflected in official government campaigns, as in the Swiss STOP AIDS campaign, which (to quote an official brochure) 'was designed to prevent AIDS, not sexuality . . . Switzerland from the outset backed the use of condoms in its campaigns, while aware this would not please everyone . . . It is true that other countries, anxious not to offend public morality, have given the condom a much lesser emphasis than in Switzerland, if any at all'.[43] This campaign grew out of the early work of gay groups in Switzerland, in particular the Swiss AIDS Foundation with its 'Hot Rubber' campaign, and has its counterparts in Germany and several other European countries. A somewhat strange exception came in The Netherlands, where for a long time governments and gay organizations promoted abstinence from anal intercourse rather than, as almost everyone else, use of condoms. A number of gay activists have criticized this stance, suggesting it showed the limits of the Dutch policy of cooperation between state and community to the extent that it seemed to prevent the creation of an independent community response.

A 'sex-positive' approach risks alienating political and broader social support, and many AIDS organizations find themselves battling to defend programs which are seen as 'obscene' or 'promoting immorality' by their opponents. The best known example of this came in the United States in 1988, when the powerful conservative Senator Jesse Helms (Republican North Carolina) was so enraged by material produced by GMHC — a recipient of federal anti-AIDS funds — that he introduced an amendment prohibiting the use of federal funds 'to provide AIDS education, information or prevention materials and activities that promote or encourage, directly or indirectly, homosexual activities'. This was strongly supported by the Senate, and has been a real barrier to the production of materials of the sort which are common in, say, Germany or Australia.[44] Similar restraints have, of course, been applied elsewhere. In

AIDS Supporting and Education Trust was ruled to be 'offensive and pornographic' by the country's Publications Appeal Board, which cited the Bible as evidence that it was wrong 'to promote "loose" sexual relationships, fornication and the practice of homosexualism (sic)'.[45]

I cannot resist retelling one of the more famous Australian episodes around a peer education campaign which brings together themes of empowerment, positive attitudes towards sex and the politicization of a group through reactions to its education work. What became known as 'Two Boys Kissing' was a safe sex advertisement developed by the Youth Team of the Victorian AIDS Council in July 1990. It showed a picture of two young men kissing — 'boys' is misleading; they appear to be post-teenage — and under this image the words: 'Making the first move might be scary, but more guys than you think have sex with other guys. It's natural and if you're safe you'll have a great time.' When the magazine *TV Week* refused to run the advertisement it became a major media story, and under political pressure the State Health Minister made clear her opposition. The decision of *TV Week* was upheld by the Advertising Standards Council, an industry watchdog, but this decision only strengthened the determination of VAC to pursue work with young men, and to maintain a 'pro-sex' strategy.[46] The full political impact of the campaign did not occur for three years, when a new conservative Minister removed Aus$40 000 from VAC's government grant for education, but most people in the organization felt this was well worth the attention the issue had generated.

In countries where HIV infection is spread widely throughout society, there has been considerable emphasis on educating both women and youth. Again the emphasis is often on increasing self-esteem and community pride. The central public health lesson of the epidemic is that it is impossible to offer effective prevention and care services without becoming involved in community development, and thus in forms of political intervention. But we should beware of accepting too easily a Western position that condemns all attempts to reduce sexual partners, and to stress monogamy, as necessarily repressive. In societies where women are denied any sexual or social autonomy, attitudes which might strike a Westerner as overly moralistic may be a necessary means of affecting change; it may, for example, seem easier to campaign for reducing partners than for the use of condoms, which may be either unobtainable or unacceptable.[47] To be effective, such campaigns need target men rather than women, and are likely to run into far greater resistance in practice than are those advocating the use of condoms.