

On the fault-line: the politics of AIDS policy in contemporary South Africa

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While President Mbeki's statements questioning conventional views on the causes of AIDS may have seemed bizarre to many, these statements have a much clearer logic when seen as part of an ongoing struggle between various players in South Africa. Notwithstanding the joint action around the court challenge to affordable drug prices by the pharmaceutical industry (in March 2001), the AIDS policy process in South Africa has been marked by very public disagreement and almost complete non-accommodation between senior African National Congress (ANC) politicians and a range of non-governmental actors in South Africa. In a cycle established by early criticism of the new government by non-governmental AIDS players, public debate on AIDS has been dominated by a series of responses and counter-responses in which actors have competed to set the agenda for AIDS in South Africa. Many of the presidential and ministerial state interventions on AIDS can be seen as countering the attempts by activist and scientific communities to influence the policy terrain, despite the historical affiliation of the latter to the mass democratic movement of the pre-1994 period. The prominence of AIDS in this country has been as much about conflict between the politicians and other actors as about the growing realization that millions of young people in South Africa are infected with HIV and may die in the next ten years.

In a context where the state has had the power to implement major policy initiatives such as the macro-economic Growth, Employment and Redistribution (GEAR) strategy, why has conflict around AIDS policy persisted as "high politics"?¹ What explains the apparent inability of the state to exercise effective leadership and deal decisively with AIDS, the particular strategies it has adopted in relation to AIDS activists and scientists, and the ability of these activists and scientists to apply ongoing pressure and even precipitate a political crisis at the centre of power in the new state?

This paper attempts to answer these questions through a closer examination of the various responses to AIDS in South Africa, as a distinct set of social relations within the post-apartheid landscape. The particularity of the AIDS world or field is partly explained by the emergence of a fatal disease that has crossed, and generated responses that cross, many conventional social

boundaries, involving a wide variety of actors; and partly by the fact that it has spawned both local and global social movements. As a consequence the AIDS field concentrates within it distinct forms of power, which have been successfully exercised in relation to the state. On the other hand, despite attempts to centralise decision-making on AIDS in the presidency (possibly pointing to a general political trend), the state itself is by no means united behind the president's positions on AIDS. A degree of bureaucratic and political independence is evident from the increasing amount of resources being allocated for HIV and the decision by certain provincial governments to defy national policies on the use of anti-retroviral drugs. Contestation within the state, although less visible, has thus significantly strengthened the position of non-governmental actors.

This paper begins by outlining the chronology of contestation around AIDS in South Africa since 1994. This is followed by a mapping of the actors and the positions taken by political leaders and non-governmental AIDS actors in this contestation. The nature of power in the AIDS field is then considered, and some conclusions drawn about social mobilization and the desirability of political leadership in the context of AIDS.

The notion of a distinct AIDS field in South Africa mirrors, and is not unconnected to, the manner in which AIDS has played itself out globally. This paper draws extensively on Epstein's critical analysis of the science and politics of AIDS in the US (Epstein 1996).

Policy Contestation around AIDS since 1994

In the period from 1990, when the ANC and other political organisations were unbanned, to 1994, when a new government was elected, large numbers of people were involved in debating the principles and content of an appropriate response to AIDS in South Africa. In 1992 an umbrella body, the National AIDS Committee of South Africa (NACOSA) was formed to coordinate a process of policy development and the writing of an AIDS Plan. The AIDS Plan was a detailed, lengthy document, subsequently viewed as vastly overestimating the implementation capacity of the new government (Schneider and Stein 2001). However, the importance of the AIDS Plan lay firstly in the participatory manner in which it was developed, involving large numbers of people over several years, thus establishing an expectation of future participation in AIDS policy; and secondly, in the fact that it formalised a set of principles, based on the protection of human rights, for the response to AIDS in South Africa.

Although adopted by the Department of Health in 1994, the implementation of the AIDS Plan rapidly became subsumed by the enormous tasks of government restructuring in the early post-1994 period (*ibid.*). In addition, in contrast to the period leading up to the change of government, there was little discussion or

contact with the range of non-governmental AIDS actors regarding the implementation of an AIDS policy once the new government was in place. Reflective of the style of governance in the national Department of Health, the then Minister of Health commented that “AIDS does not consult, it infects people” (*Mail and Guardian*, 9 February 1996).

It is therefore not surprising that when knowledge of a ministerial decision to grant a contract of R14 million to create an AIDS musical (*Sarafina II*) became public in early 1996, there was an outcry from a range of non-governmental players. Reactions concerned the apparent secrecy of the process, the amounts of money involved and the problematic AIDS messages that the musical conveyed. *Sarafina II* rapidly took centre stage of politics, generating a huge amount of negative media attention for government and becoming the subject of the first investigation by the new office of the Public Protector. The latter wrote a report that was highly critical report (Public Protector 1996), and President Mandela declared *Sarafina II* one of the ANC’s “three mistakes” of 1996 (*Cape Argus*, 20 January 1997). Despite this admission, the events around *Sarafina II* signaled the “demise of a shared vision for AIDS in the country” (quoted in: Marais 2000:34) and effectively triggered a cycle of conflict between the state and other AIDS players in South Africa.

Shortly afterwards, in an apparent attempt to recapture government legitimacy, a Cabinet press release announced the development of a South African treatment for AIDS (*The Cape Times*, 17 February 1997). A group of researchers from the University of Pretoria had approached the Minister of Health for funding of their “breakthrough” AIDS treatment, known as Virodene (an organic solvent). However, the biomedical community and the drug regulatory authority, the Medicines Control Council (MCC), greeted the news with skepticism. Based on insufficient evidence of its efficacy and serious doubts about its safety, both the University of Pretoria’s ethics committee and the MCC turned down applications for further testing on humans. The Minister of Health and the Deputy President (Mbeki) accused the medical profession of retarding access to life saving therapies. After another prolonged period of media coverage, the drug eventually lost credibility as a viable treatment for HIV/AIDS.

Also early in 1997, the Director-General of the Department of Health issued a statement (van der Linde 1997:12) proposing that “that the attitude towards the whole issue of confidentiality should perhaps be reviewed”, suggesting that prejudice and discrimination were being perpetuated by “keeping HIV and AIDS in the closet”, thus implicitly calling into question the principle of individual rights underlying the AIDS Plan. In August 1997 against the advice of activists and scientists in the AIDS field (including epidemiologists in the Medical Research Council, clinicians, NGOs and the government’s own AIDS Advisory Committee), the Minister of Health unexpectedly announced that AIDS was to be made notifiable. This announcement was made at a large report back meeting

of the National AIDS Review, one of whose purposes was to create a better dialogue between government and non-governmental actors (*The Star*, 26 August 1997).

In March 1998 results of a trial conducted in Thailand were announced, showing that a short course regimen of AZT (an anti-retroviral also known as Zidovudine) reduced mother-to-child-transmission (MTCT) of HIV by 50 per cent. The results were subsequently published in the scientific literature (Shaffer *et al.* 1999). These findings represented one of the first significant interventions, affordable and feasibly implemented on a large scale through the public sector, for the children of people already infected with HIV. During the course of 1998, including at the launch the Presidential Partnership Against AIDS in October 1998, representatives from the National Association of People Living with AIDS (NAPWA) and AIDS researchers made calls for the availability of AZT for pregnant women. The government's national HIV/AIDS & STD Directorate had already drafted an outline of possible policy directions, recommending that "anti-retroviral therapy for HIV infected pregnant women be considered" (Department of Health 1998: 1), and provincial governments had begun preparations for pilot sites. These plans were abruptly halted, apparently through action at senior political level. Significantly, the Western Cape Province, controlled by a party different to the ANC, went ahead and implemented a MTCT prevention programme based on AZT. Elsewhere, however, the use of AZT was rejected, initially on the grounds of affordability, and then on the grounds of safety. The latter issue reflected the views of the so-called "dissident" AIDS scientists, who were questioning the link between HIV and AIDS, and who suggested that the toxicity of AZT may be the cause of AIDS. MTCT became the first campaign issue of the Treatment Action Campaign (TAC) when it was established as an alliance of three activist groupings in 1998.

Following national elections in mid-1999, a new minister adopted the recommendations of the South African Law Commission and gazetted regulations protecting confidentiality and consent, effectively countering moves by the previous minister to make AIDS notifiable. These were welcomed by the TAC (Treatment Action Campaign 1999). In addition, behind the scenes contact between activists and the new ministry gave hopes that an MTCT programme would be implemented. This was boosted by the results of a Ugandan trial, released in July 1999 showing that single dose nevirapine (an anti-retroviral drug) reduced MTCT of HIV by 47 per cent (Guay *et al.* 1999). However, despite an official delegation to Uganda to discuss both this and Uganda's success in reducing the prevalence of HIV, government announced that nevirapine for MTCT would only be considered once the results of South African trials had been published. Arguments about toxicity surfaced once again, as did the issue of drug resistance.

In early 2000 government statements suggested that the link between HIV and AIDS needed to be re-examined. Mbeki, now President, had been in contact with prominent AIDS dissidents, whose website he possibly encountered “in one of his frequent internet trawling sessions” (*Village Voice*, 15–21 March 2000). A Presidential AIDS Advisory Panel was convened in May 2000, consisting of leading “dissident” and “orthodox” scientists to consider the causes of, and appropriate solutions to, AIDS in the African context. A public polemic between government and scientists ensued, culminating in the Durban Declaration, an international petition of more than 5,000 scientists in support of the “orthodox” views of HIV/AIDS, launched at the International AIDS Conference held in Durban in July 2000, and published in the prestigious science journal, *Nature*. The Durban Declaration was dismissed by a presidential spokesperson who indicated that “it will find its comfortable place among the dustbins of the office.” (*Independent Online*, 3 July 2000).

In the meantime both medical researchers and key NGO groupings (NAPWA, TAC, AIDS Consortium) were excluded from the new South African National AIDS Council (SANAC), established by the presidency in January 2000 and chaired by the Deputy-President.

Following internal pressure within the ANC and an interview with Time Magazine in September 2000, perceived by many to be damaging, Mbeki apparently told the ANC National Executive that he was to withdraw from public debate over the science of HIV/AIDS. After the reporting of local data on nevirapine at the Durban AIDS Conference, and threats of legal action by the TAC, the government announced it would convene a meeting to discuss the introduction of nevirapine. This created the hope that a new period of accommodation between the state and others might follow. The TAC entered into an alliance with the Congress of South Africa Trade Unions (COSATU) and international players to support the government in the March 2001 court hearing brought by the multi-national pharmaceutical industry to prevent regulatory measures to reduce the cost of AIDS drugs.

Despite dramatic drops in the prices of anti-retroviral (ARV) drugs around the time of the court case, however, government indicated that ARV therapy (other than for MTCT) was still not affordable or feasible in the public health sector. The TAC countered by announcing its intention to launch an alternative AIDS Treatment Plan for the country, which would include consideration of ARVs in the public sector.

After various delays, the nevirapine pilot sites were implemented in the second quarter of 2001. In August 2001, the TAC lodged court papers against the Minister of Health for failing to adequately implement the prevention mother-to-child transmission of HIV.

Finally, in September 2001 the government attempted to delay the publication of a report by the Medical Research Council, which showed a rise in adult mortality, most likely due to HIV. Drawing on 1995 cause-specific mortality statistics, President Mbeki wrote a letter to the Minister of Health questioning whether AIDS was indeed the main cause of mortality, and suggested that spending priorities in the Department of Health be reviewed (*Business Day*, 10 September 2001).

This chronology of policy contestation is summarised in the table below.

Chronology of policy contestation on AIDS since 1994

1996	Sarafina II musical criticised
1997	Virodene announced
1997	AIDS made notifiable by the Minister of Health
1998–9	AZT questioned
2000	Launch of National AIDS Council by the government, excluding activists and scientists
2000	Cause of AIDS questioned by the presidency; Durban Declaration by scientists
2001	Use of ARVs in the public sector rejected by the Ministry of Health
2001	Delays in implementation of MTCT by the Ministry of Health
2001	Mortality statistics questioned by the presidency

The Stances of the State on AIDS

It is possible to see in the above events the generation of a vicious cycle of growing alienation between key members of the state and non-governmental AIDS actors. In this cycle, initiated by Sarafina II, interventions by the Ministry of Health and the presidency appear increasingly determined by the dynamics of response and counter-response within the AIDS field itself. However, these state actors clearly have a degree of agency in their choice of strategies on AIDS. What have these strategies been and what underlies the choice of strategy?

Strategies

The brief of the Presidential AIDS Advisory Panel was to address, amongst others, the following:

- Why is HIV heterosexually transmitted in sub-Saharan Africa, while it is largely homosexually transmitted in the Western world?
- The prevention of HIV/AIDS, particularly in the light of poverty, the prevalence of co-existing diseases, and infrastructural realities in developing countries.

Implicit in this brief was a desire to establish the reasons for the explosive spread of HIV in Africa, and to define a response appropriate to the social and economic context of the continent. It correctly points to a real lack of explana-

tions for the pattern of the HIV pandemic, particularly in Southern Africa. For example, a recent study comparing African cities with high and low HIV prevalence rates found that individual sexual behaviour variables could not account for differences in HIV prevalence between cities (Lagarde *et al.* 2001). Similarly, the dominant “behaviour change” models of the public health community have failed to address the broader structural problems fuelling the HIV pandemic. Scientists and activists calling for access to anti-retroviral drugs have thus been criticised for presenting drugs (or treatment) as the solution, rather than addressing poverty as the cause.

The search for appropriate responses has also led to questioning of the rights based approaches to HIV advocated by various UN agencies. Placing limits on patient confidentiality and compelling disclosure through notification are frequently invoked as measures to address the silence and denial of AIDS in Africa, and have emerged at regular intervals in the context of the Southern African Development Community (SADC). Several African countries have instituted moves to criminalise the deliberate spread of HIV. These attitudes possibly reflect an antipathy to the perceived imperialism of global norms, established by the “homosexually transmitted”, “Western” epidemic, and a desire to invoke more classic public health measures of “containment and control” (Kirp and Bayer 1992). Support for such measures is widespread amongst health workers and even amongst senior cadres in the health sector.²

The openness to considering Virodene can be read as championing African-initiated science in the context of the agenda for an African Renaissance. There appear to be interesting parallels between Virodene and the testing of a veterinary drug for HIV in humans in Kenya in the early 1990s (Hyden and Lanegan 1993). The Kenyan drug, which became known as “Kemron”, was launched by President arap Moi at the 10th anniversary of the Kenya Medical Research Institute. Although the drug was subsequently found to be ineffective, a Kenyan company was created to promote the drug and “observers could not escape noticing that President arap Moi made it clear to Kenyans ... that those who expressed doubts about Kemron were not true patriots.” (*ibid.*:62).³

Apart from pointing out the necessity of an African response to AIDS, another key strategy of the state has been to mount an intellectual critique of scientific certainty and control. In defense of the Presidential AIDS Advisory Panel, Mbeki commented: “... you had the US government issue new guidelines about the use of anti-retroviral drugs — radically different to what had been the practice before ... So they changed the guidelines, which is fine. What they are raising fundamentally, is that *science does not have enough answers to deal with this question.*” (Transcript of an e-TV interview with Deborah Patta, Third Degree, 24 April 2001, italics added). Articles reflecting the scientific uncertainty around anti-retroviral therapy have featured on a regular basis in ANC

Today, the web-based newspaper of the ANC (*ANC Today*, 16–22 February 2001; *ANC Today*, 20–26 April 2001).

In a detailed analysis of AIDS controversies in the US, Epstein suggests that an important aspect of the dissident position was to expose the messy processes within the “black box” of scientific fact-making, where “contingency is forgotten, controversy is smoothed over, and uncertainty is bracketed” (Epstein 1996:28). Once HIV was accepted internationally as the cause of AIDS in the mid to late 1980s, the scientific community closed the black box on the debates of cause. Despite the established credentials of scientists such as Duesberg, they had enormous difficulty in presenting contrary views through the mainstream scientific literature. The dissidents thus cast themselves as heroic, anti-establishment figures, in the moulds of Darwin and Galileo “equating ‘normal’ science with dogma, superstition, and intellectual stagnation” (ibid.:152). For some years (in the late 1980s and early 1990s) the dissidents were able to rally considerable scientific and popular support behind them in the US and elsewhere.

In its willingness to entertain the AIDS dissidents, the South African presidency was thus not only aligning itself to certain scientific views but also to a critique of the political economy of biomedical research. Dissidents have been hailed as revolutionary in South Africa.⁴ Scientists and activists calling for anti-retroviral treatment have also been projected as playing into the hands of the profit-making multi-national pharmaceutical industry, therefore anti-poor and elitist (Mankahlana 2000; *ANC Today*, 16–22 February 2001; *ANC Today*, 18–24 May 2001).

If the state has played the dissident card in the national context, internationally its contribution and presence has been the prototype of mainstream international approaches to HIV. South African officials participated in drawing up the Abudja Declaration on HIV/AIDS, Tuberculosis and Other Related Infectious Diseases (Organisation of African Unity 2001). This Declaration calls for, amongst others, increased expenditure on health programmes (up to 15 per cent of national budgets) and the creation of a Global AIDS Fund for anti-retroviral programmes in Africa. After the United Nations General Assembly Special Session (UNGASS) on AIDS in June 2001, the Minister of Health issued a statement in which she endorsed the call for national poverty eradication strategies and access to treatment with quality-controlled anti-retroviral therapy (Department of Health, 2001).

Many would see in the contradictory stances of political leaders (e.g. unquestioning support for virodene vs. extensive criticisms of anti-retrovirals; a focus on poverty as the cause of AIDS vs. the realpolitik of macro-economic adjustment), an attempt to deny the enormity of the problem of AIDS in South Africa, and the challenges it raises for the allocation of resources, nation building, and, ironically, the need to address the fundamentals of poverty and inequality.

Equally plausible is that the conflict around AIDS, in the context of an emerging post-apartheid state, represents a battle between certain state and non-state actors to define who has the right to speak about AIDS, to determine the response to AIDS, and even to define the problem itself.⁵ Ultimately it can be seen as an attempt on the part of the political leaders to establish who will legitimately be accepted as civil society partners with the new state and the extent to which non-state actors can define government policy. High level state interventions in the AIDS field have thus perhaps less to do with the differences in the content of policy than with a discomfort, and at times active exclusion of, social movements that express certain styles of activism and that fall outside of the immediate networks of political patronage and influence within the tripartite alliance.⁶

Using Bourdieu's (1986) typology of "capitals", contestation in the AIDS field, from the perspective of political leaders, is over symbolic capital: the legitimate right to hold and exercise power. "Capitals" are resources which yield power and include economic (material resources), cultural (educational credentials) and social (durable networks of relationships of mutual acquaintance and recognition) capital. Symbolic capital is the form taken by all capitals when their possession is perceived to be legitimate. Although key civil society actors in the AIDS field may not have been accepted by the state as serious contenders in the policy process, their ability to mobilise and convert "capitals" into political and even economic power has forced an engagement with them.

Differences within the state

The catapulting of AIDS into the arena of high politics has undoubtedly undermined the ability of the state to mobilise and lead a united response to AIDS in South Africa. However, conflict has tended to occur largely in the political domain and at national level, involving mainly the presidency and the Health Ministry, with the day-to-day bureaucratic realm and provincial governments functioning relatively autonomously and sometimes in contradiction to central political stances.

When the President questioned the link between HIV and AIDS, government did not stop buying condoms or STD drugs. In reality, increasingly large sums of money are being allocated and expended on AIDS programmes by government based on the most conventional of public health assumptions about the link between HIV and AIDS, the need for behaviour change, and the role of STDs and condoms.

In 2000 the national government "top sliced"⁷ R75 million (at the time, approximately US\$ 8 million) for an National Integrated Plan (NIP) on AIDS involving the Education, Health and Social Development Departments and focusing on life skills education, voluntary counseling and testing, and

community based care and support. This top slice was projected to rise to R296 million by 2003/4 (Hickey and Whelan 2001). Recent media reports (*Mail and Guardian*, 21 September 2001) suggest that the amount to be allocated to AIDS may in fact be considerably higher — R2.7 billion over the next three years. The latest proposals apparently include funding for pilot anti-retroviral therapy sites, and are partially a response to growing pressure from below, as the impact of AIDS on the health system starts to be felt. The national top slice does not include large amounts of funds allocated to vaccine research, routine national HIV/AIDS programme funding, special grants to multi-media media campaigns such as Lovelife, and provincial allocations.

The existing and proposed allocations of resources signal some degree of independence from the presidency in the bureaucratic realms. This detachment from the political domain is also reflected in the Department of Health's regular HIV/AIDS Newsletter, which focuses on the day-to-day activities of the AIDS and TB programmes and does not mention or engage with the broader political debates. The AIDS programme has also collaborated actively in the Diflucan⁸ donation programme, initiated as a direct result of activist campaigning, and is providing logistical support to MTCT programmes.

This independence also exists at the political level — in the face of ministerial and cabinet disapproval, the Western Cape Province, and even one ANC-aligned province (Gauteng), have extended distribution of anti-retroviral medication to prevent MTCT beyond designated pilot sites. AIDS has also been an important source of tension within the tripartite alliance with COSATU, in particular, openly contesting the stances of ANC leaders on HIV.

Non-governmental actors

Since 1994, the non-governmental AIDS world in South Africa has cohered around two key groupings of actors:

- An activist grouping consisting of a number of organisations and alliances. They include the National AIDS Committee of South Africa (NACOSA), active already prior to 1994; The AIDS Consortium, a well established networking and information dissemination NGO, formed in 1992 and based in Johannesburg; The National Association of People Living with AIDS (NAPWA); and since late 1998, the Treatment Action Campaign (TAC). The activist community has been strongly influenced by a legal/human rights presence in the field.
- Basic and public health scientists based in academic institutions — the Medical Research Council and universities (predominantly in the metropolitan areas of Durban, Johannesburg and Cape Town). The South African biomedical community has and is playing a crucial role in research (both nationally

and internationally) around mother-to-child-transmission of HIV and AIDS vaccines.

Each grouping has links with a range of other actors (clinicians, CBOs and NGOs, local AIDS support groups, policy researchers) and, through bonds formed over the years, to each other. Both have numerous international connections.

AIDS activism

AIDS in South Africa was first seen in the early 1980s and was linked biologically to the epidemics in the USA and Europe affecting predominantly gay men and injecting drug users. This was followed by an epidemic starting in the late 1980s and linked biologically to AIDS descending from Central and East Africa. Until the mid-1990's, when "HAART" — highly active (triple) anti-retroviral therapy — became widely available in industrialised societies, AIDS was as much a death sentence for a white middle class gay man in New York or Cape Town as for a black working class woman in Kampala or Johannesburg. This unusual commonality of experience, at both the individual and the community level,⁹ between North and South, straight and gay, white and black, has facilitated bonds and forms of action across numerous of the classic social divides.

The mobilisation of an AIDS movement in the late 1980s in the US and other industrialised societies in many ways set the scene for AIDS activism in South Africa. The connections between movements occurred through networks of gay activists and the participation of South Africans in international AIDS conferences, where the cultural forms of Northern AIDS activism were expressed and observed at close range.

As an epidemic strongly associated with homosexuality, AIDS in the First World fuelled and built on traditions of gay identity politics and mobilisation. This social movement was dominated by white, middle class men "with a degree of political clout and fundraising capacity unusual for an oppressed group" (Epstein 1996:12). Its association with intellectuals, artists and professionals gave it the cultural capital to grapple with the complexities of the emerging science of HIV/AIDS. AIDS activists thus became highly credible technical commentators on AIDS, able to swing public opinion in their favour and able to formulate specific and targeted campaigns on the basis of their knowledge.

Organisationally, this movement is most closely linked to ACT-UP (AIDS Coalition to Unleash Power), which formed chapters in New York and San Francisco in the late 1980s, followed by the major cities of the First World. Drawing on roots in the gay, feminist, anarchist and peace movements, ACT-UP described itself as: "a diverse, non-partisan group of individuals united in anger and committed to direct action to end the AIDS crisis. We advise and inform.

We demonstrate.” (www.actupny.org) On the one hand, acts of civil disobedience relied on various forms of “direct action” (storming of meetings, offices, drug companies, medical conferences) and, on the other hand, an accumulation of knowledge and expertise enabled activists to negotiate with scientists, the medical profession and drug regulatory agencies. Epstein (1996:32) describes this style of activism as combining “ingenuity, brashness, aptitude, and muscle”.

The mobilisation achieved by ACT-UP and other organisations that were spawned in its wake forced changes at many levels: in the conduct of scientific trials, the approval of drugs and in the representation of AIDS activists as equal partners in scientific forums. As activists gained the right to participate in the formal processes of institutions such as the Federal Drug Administration and the International AIDS Conferences, the social movement itself became segmented into “professional” activists as “insiders”, and “lay” activists as “outsiders”. The principled oppositional stances and styles of protest at the core of ACT-UP’s identity have thus appeared more and more out of place in forums such as the World AIDS Conference where PWAs, gay activists, and NGO representatives have become a permanent feature of the planning and running of the conference.

While the AIDS movement combined “expressive, instrumental and identity oriented goals” (Epstein 1996:220), its content was strongly associated with obtaining access to drugs. The refusal to see those who were infected with HIV/AIDS as victims, and the view that nothing could be done to combat the disease, shaped the focus on treatment and in this respect the AIDS movement fundamentally altered the practice of science and medicine. A key achievement was the institution of parallel track programmes, where promising drugs still undergoing lengthy and rigorous processes of testing in trials were released early to non-trial participants.

By the mid-1990s the AIDS movement was in decline in the US, partly because the specific forms of treatment activism had run their course, and partly because it was unable to confront the broader socio-political challenges brought by its membership in black and Latino communities. However, ACT-UP has recently re-emerged as a player in support of treatment access in middle and low income countries, and its styles of activism have found renewed relevance in the context of anti-globalisation movements.

The readiness by NGOs in South Africa to provide an open and early challenge to the new government around Sarafina II, local demonstrations against drug companies, the “illegal” importation of a generic form of fluconazole by the TAC, and the focus of activism on treatment all reflect what was learnt and understood about AIDS activism from the North. AIDS in South Africa has thus been a beneficiary of “social movement spill-over” (Meyer and Whittier 1994) in the same way that the AIDS movement benefited from prior mobilisation around gay struggles.

However, AIDS activism in South Africa cannot be seen as a simple reflection of movements elsewhere. The social movement around AIDS in South Africa, even the gay rights elements of it, have roots in the mass democratic movement¹⁰ of the 1980s and 1990s, giving it a wider social base and a need to frame AIDS struggles within broader political and economic struggles.

Generally speaking, AIDS activism in South Africa has evolved in two strands. The first strand is rooted in the anti-apartheid health sector organisations, which addressed AIDS as an extension of their other activities. The 1990 Maputo Conference on Health in Transition in Southern Africa, considered a milestone in health sector policy development and which brought together the internal health movement¹¹ and the external ANC, had a special session focusing on AIDS. It produced the Maputo Statement on HIV and AIDS in Southern Africa (Stein and Zwi 1990). This statement rejected a “narrow biomedical” focus on AIDS and located it within the “broader struggle for sociopolitical change” (ibid.:137). It called for the establishment of an “AIDS Task Force” to coordinate actions within South Africa. Shortly afterwards, the National Progressive Primary Health Care Network (NPPHCN) initiated a large national AIDS community mobilisation project, which existed for a number of years.

Also at this time the liberation movements were unbanned and returned to South Africa. In October 1992, the ANC and the apartheid government’s Department of Health jointly convened a large conference at which the National AIDS Convention of South Africa (NACOSA) was launched. NACOSA was an inclusive umbrella body whose purpose was to define the principles of and a strategy for a coherent and comprehensive response to AIDS in the country. It coordinated the writing of an AIDS Plan, finalised in 1994 and adopted by the new government. In the post 1994 period, NACOSA’s national profile has gradually diminished although it continues to have a presence in certain provinces (notably the Western Cape) and is currently linked to the community education efforts of the South African AIDS Vaccine Initiative.

The second strand of activism emerged from a legal and human rights base, also established around the time of political transition in South Africa. The AIDS Consortium (of which the founding document was an HIV and AIDS Charter of Rights), the AIDS Law Project and the National Association of People Living with AIDS (NAPWA) form part of this tradition. Activists in these organisations were instrumental, through networks such as the Coalition on Gay and Lesbian Equality (CGLE), to the inclusion and retention of sexual orientation as one of the grounds for non-discrimination in the new South African Constitution. While focused on issues of legal and social equality (including gay rights), these organisations have increasingly linked rights such as autonomy and confidentiality to broader social and economic rights (Heywood and Cornell 1998).

The Treatment Action Campaign was launched as a coalition of the legal and human rights groupings in the AIDS field on International Human Rights Day in December 1998, and is currently the most high profile contemporary expression of an AIDS social movement in South Africa. Resonant of the AIDS movement in the First World, the “TAC campaigns against the view that AIDS is a ‘death sentence’ ” (www.tac.org.za) and, through better access to treatment, aims to prevent a fatalistic attitude to AIDS in South Africa. By campaigning for access to treatments in the public sector and for improved “affordability and quality of health-care access for all” (*ibid.*), it allies itself to the poor rather than the middle classes. Since 2000, the TAC has formed an alliance with COSATU, the trade union partner in the Tripartite Alliance (Vlok 2000), with whom it now runs most of its campaigns. While still focused on access to treatment (including anti-retroviral medication), the TAC has increasingly linked these issues to broader anti-poverty demands, such as the Basic Income Grant. The TAC can thus be seen as aligned, if not formally linked, to an assortment of actors emerging in opposition to the government’s macro-economic policies of fiscal restraint and privatisation.

A feature of AIDS activism in South Africa is its pro-knowledge stance and its ability to obtain and transmit expert knowledge about scientific and policy developments. This stems from a base in the middle class legal, research and gay communities and is also undoubtedly inspired by highly effective lay media groups such as AIDS Treatment News and Project Inform in the United States. A detailed understanding of South African trials to prevent mother-to-child-transmission and specific drug policies and legislation have been key underpinnings to local strategy. The AIDS Consortium has been extremely effective in gathering information from a wide variety of sources and making it accessible to large numbers of people. In recent years email list servers, culling information from a range of consumer and biomedical sources and distributed on an almost daily basis, have no doubt facilitated global mobilisation in support of the TAC.

The treatment campaigns in South Africa over the last few years have connected with global campaigns for drug access by international NGOs such as *Medicins Sans Frontieres* (MSF), creating a powerful new international alliance. Together with groups such as OXFAM and Ralph Nader’s Consumer Project on Technology (CPT), MSF has sought to prevent the multi-national pharmaceutical industry from exploiting emerging agreements¹² through the World Trade Organisation that seek to block the production of generic medicines in middle income countries such as South Africa, Thailand, Brazil and India. Bringing in international gay networks and providing a renewed focus for certain chapters of ACT-UP, the alliance has been formalised in a campaign (the Global Treatment Access Campaign) and organisationally in the Health GAP (Global Access Project) Coalition. This alliance has emerged in parallel to, and is often critical of, private sector accommodation by a variety of UN based public-private initiatives.¹³

The holding of the International AIDS Conference in Durban in 2000, coinciding with the Mbeki's dissident stance on HIV, put AIDS in South Africa and the lack of access to anti-retrovirals on the front page of newspapers worldwide. The court hearing of the case by the Pharmaceutical Manufacturer's Association against the South African government provided the political moment to focus a global campaign. In the week the case came to the Pretoria High Court (5 March 2001) 27 protest activities, involving 12 countries (including the US, Canada, UK, Brazil and Philippines) were reported on the TAC website. Clearly sensitive to negative public opinion, several drug companies immediately announced major price reductions in ARVs.

Scientists

South Africa has a well-established biomedical AIDS research tradition. The Medical Research Council (MRC) initiated an AIDS programme in the late 1980s, conducting some of the earlier epidemiological and health promotion research and based predominantly in the KwaZulu-Natal and Western Cape Provinces. The MRC is still a central player in the field and is coordinating a large programme of research on AIDS vaccines. The South African AIDS Vaccine Initiative (SAAVI) is a public interest, multi-centre collaborative project launched in 1999 with state and international donor funding. It aims to develop and test vaccines relevant to the predominant strain of virus in the region and to locate the intellectual property arising from the initiative in the public domain (Galloway undated). It is a South-based initiative but with links to research institutions and biotechnology companies in the North. Another focus of research has been in the clinical arena, with a strong local agenda, starting in the early 1990s, on the prevention of mother-to-child transmission, based in the metropolitan areas of Durban, Johannesburg and Cape Town.

The biomedical field has been as international in orientation as the activist field. The local research infrastructure is able to access large amounts of international funds available for AIDS research, and even to play a role in shaping global research agendas. For example, UNAIDS has supported trials of anti-retroviral therapy to prevent mother-to-child-transmission of HIV by groups at Baragwanath Hospital (Soweto) and King Edward Hospital (Durban); and the MRC is a key actor in the International AIDS Vaccine Initiative (IAVI), a global public-private partnership attempting to address the general market failure around the development of vaccines for HIV.¹⁴

Most of the prominent scientists working on AIDS emerged from the progressive health movement of the 1980s. Links between the scientific and activist fields have thus been shaped by common historical affiliations with the mass democratic movement and have been further consolidated by common participation in local and international forums such as NACOSA and AIDS conferences.

The approach to HIV by the South African biomedical community reflects on the one hand ideal and somewhat triumphalist notions of the role of science. For example, the Durban Declaration, whilst acknowledging the role of poverty, ends with the statement: “Science [*in the form of a vaccine*] will one day triumph over AIDS, just as it did over small pox” (www.durbandeclaration.org). On the other hand is a human rights perspective on public health. The protection rather than the infringement of rights of individuals infected with HIV was established as a central tenet of AIDS prevention by Jonathan Mann, the first director of the Global Program on AIDS in the World Health Organisation. These ideas have obtained global currency through forums such as the international AIDS conferences, and locally by the active legal and human rights lobby.

International AIDS Conference

The international credibility and links of South African scientific actors in large part ensured the winning of the bid to host the thirteenth International AIDS Conference in Durban in 2000. The international AIDS conference is a large (over ten thousand people) and prestigious biannual event attracting people across the spectrum, from basic scientists to sex workers, and caters for a diverse set of needs. The initial conferences (starting in 1985) were biomedical in orientation; broader representation of people and interests only emerged in the early 1990s as a result of sustained activist pressure for lay participation in scientific debates about AIDS. This is reflected in the complex governance of the AIDS conferences. The “ownership” of the conference lies with the International AIDS Society (IAS), which co-hosts the conference with UN agencies (UNAIDS), international AIDS NGOs, and the country where the conference is held. The pharmaceutical industry is a major sponsor of the event although it does not play a role in designing the official programme.

While numerous other specialist scientific AIDS forums have been created over the years, the international AIDS conference is still regarded as the key event in the AIDS calendar. Since the early 1990s South African scientists and activists have made almost ritual pilgrimages to these conferences as well as to the smaller regional conferences held in alternate years.

The Durban conference was significant in a number of ways. It was the first of the international AIDS conferences to be held in the South, and effectively shifted attention to the issues affecting Southern Africa. It was also a moment of international agenda-setting around vaccines, MTCT, and the need to face the global inequalities in treatment for AIDS. Up until then, the most prominent international attempt to focus on Africa had been the International Partnership Against AIDS in Africa (IPAA), a UNAIDS initiated public-private partnership involving governments, NGOs and the pharmaceutical industry. Accepting both the high prices of anti-retrovirals and market failure in the development of

vaccines, the IPAA called for access to low level AIDS care, individual behaviour change and greater community and political commitment by African governments (Baylies 1999). However, the events at the Durban conference, including a march by the TAC and a speech by Justice Edwin Cameron¹⁵ “forever changed the quiet acceptance of the status quo on the part of both developed and developing countries”. (Abdool Karim and Abdool Karim 2001). In the months following the conference international activism around drug access accelerated, culminating in the implementation of differential pricing systems for anti-retrovirals, and the launch of a Global Health Fund at the G8 summit in Genoa in July 2001 for, amongst others, the purchase of AIDS drugs.

Power and the AIDS field

It has been suggested that the power of political leaders in AIDS lies in three areas: by exerting influence through formal state/government systems, by shaping discourse, and by providing moral authority (African Development Forum 2000). In South Africa, the ability of political leaders to ensure that policies are implemented through the government machinery has been limited, firstly by the structural weaknesses of the state bureaucracy inherited from apartheid, and secondly by the independence of provincial spheres of governance in a quasi-federal political system (Schneider and Stein 2001). The political prestige (and therefore moral authority) associated with leadership roles played by South Africa in UN-related AIDS initiatives has also been limited as seemingly more effective new global networks have emerged that are able to compete for credibility with established systems of global governance.

Attempts to shape discourse have served more to undermine than enhance political leadership in AIDS. The lack of consistency and coherence of this discourse, its rejection by prominent African intellectuals,¹⁶ and its failure to achieve legitimacy in the media have served more to undermine than enhance state power. Despite some degree of popular loyalty,¹⁷ political leaders appear to be caught in a cycle where they are constantly having to up the stakes, suggesting that they not only over-estimated their own power within the state but also failed to recognise the power of others. As Heywood and Cornell (1998:63) point out, the prominence of the gay community in AIDS activism established a perception that the issues were confined to “wealthy, gay white men”.

In contrast, non-governmental AIDS actors have been able to wield considerable power. Until the TAC established links with the tripartite alliance through COSATU in 1999, there were few points of contact between AIDS activists and the political domain in the post-apartheid era. Relations between AIDS researchers and the presidency reached a low point at the Presidential AIDS Advisory Panel, which severely questioned the legitimacy, neutrality and objectivity of scientists. However, the winning of the bid by South African researchers to hold the international AIDS conference provided a kind of

political trump card in relation to the state. A confluence of events around the time of the conference — the holding of the Presidential Advisory Panel, new global treatment access alliances, reporting of local trials on the use of nevirapine to prevent MTCT, international concerns regarding the African AIDS epidemic — created a purposeful and united atmosphere amongst the 13,000 conference delegates that provided a uniquely powerful rejoinder to the presidency. Ironically, the increasing alienation of AIDS researchers and activists from the political elite has freed them from the bonds of loyalty which may have constrained the voicing of criticism of the new government.

Underlying the power of non-governmental actors is their access to both cultural and social capital, generated by the linking of multiple social dimensions and spaces: marginalised gay men and township youth; middle class expertise and popular mobilisation; individual and broader social and economic rights; activists and scientists; the North and the South; the national and the international. In the literature on social capital, “bridging” networks such as those commonly found in the AIDS field, are considered to be particularly effective forms of resource mobilisation. These social networks have been facilitated by physical networks of electronic communication and vastly increased access to information through the internet.

The exercise of power by non state actors has also been made possible by the strategic and tactical use of what Kingdon (1995) refers to as “focusing events” of which the Durban AIDS conference and the 2001 drugs court case are good examples. Also important have been: alliance building with internationally “credentialed” groups such as *Medicins Sans Frontieres*, winners of the Nobel Peace Prize; active support from an independent local media, seeing in AIDS an opportunity to call the new state to account (Marais 2000); and finding concrete targets for short term mobilization.

Conclusions

The challenges posed by AIDS in Southern Africa are massive. The African Development Forum has suggested that “mobilizing public policy against HIV/AIDS is like trying to overcome illiteracy, end domestic violence, establish basic social rights, and provide universal primary health care at the same time.” (African Development Forum 2000:39); to achieve this requires both political leadership and broad social mobilization (*ibid.*).

The centrality of leadership, in particular political leadership, is frequently invoked as a necessary (and sometimes sufficient) condition for addressing the challenge of HIV/AIDS. Two recent international declarations (OAU 2001; UN 2001) have endorsed the manifesto on Leadership drawn up at the Africa Development Forum in Ethiopia in 2000. President Yoweri Museveni recently received a special award (not without some opposition from Uganda and the

Great Lakes Region) from UNAIDS “for his leadership role and excellence in the fight against the HIV/AIDS pandemic in Uganda and the Great Lakes region in general” (*The Monitor*, 24 May 2001).

However, it would seem that calls for political leadership not only place an inappropriate emphasis on the agency of national political leaders, but also project them as always willing and able to take the best possible courses of action to address the problems of HIV. What if these leaders interpret the notion of the “expanded response” as inviting certain actors and not others to participate in policy? What if the quest for leadership results in an over centralization of the response to AIDS and the subordination of effective public policy to narrow political exigencies? What if the nature of and demands made through “social mobilization” are not viewed as legitimate by political leaders?

While presidential leadership and the creation of central coordinating structures may have been enabling in some contexts, the South African experience suggests that such attempts can lead to a narrowing rather than an expansion of possibility. In other words, more diffuse, less centrally and politically driven responses may, in certain circumstances, be preferable to inappropriate political responses. State and civil society clearly need each other, but the concept of partnership cannot be reduced to a few processes such as national AIDS councils or presidential leadership. A more complex and context specific approach to partnership would entail less of a focus on leaders than the society as a whole, viewing the state as a heterogeneous set of institutions rather than simply the political leaders that head them.

The AIDS field in South Africa has demonstrated the limits to the power of political leaders and the diversity of pathways for the exercising of power by other actors, both within and outside the state. Despite the fundamental nature of the issues raised by AIDS and the long-term perspectives required to address it, the South African experience also shows that it is possible to mobilise society and create a sense of urgency to address AIDS. This has been achieved by establishing short-term goals, focused on treatment, and formulating them as demands towards the state and other actors. The considerable potential of an AIDS rights based movement to transform state institutions rests on the willingness of at least parts of the state to engage with such a movement, and the establishment of better institutional mechanisms of collaboration between state and non-governmental actors. However, in a context of poverty and inequality, AIDS rights activism cannot escape questions of broader social and economic rights, demands which may sit uneasily with the economic and political elites.

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Notes

1. High politics is defined as "the maintenance of core values — including national self preservation — and the long-term objectives of the state." (Evans and Newham 1992:127).
2. For example, in an anonymous poll, conducted by the author, of 82 senior health officials attending a conference convened by the South African Health Systems Trust in 2000, 70 per cent agreed with the statement: "confidentiality is harming efforts to prevent the spread of HIV."
3. More rooted in the established scientific community and also a South-based initiative (albeit with Northern partners) is the South African AIDS Vaccine Initiative (SAAVI), which has received a large amount of funding from the state.
4. In early 2000, Deputy President Jacob Zuma apparently singled out "the group ACT-UP San Francisco for praise and comparing its belief that HIV is harmless to Galileo's 17th century crusade to prove that the earth rotates around the sun" (*Newsday*, 23 April 2000).
5. A very similar view is taken by Epstein (1996:30) of the US: "Controversies about what causes AIDS are simultaneously controversies about scientific controversies *and* how they should be adjudicated — controversies about power and responsibility, about expertise and the right to speak."
6. The tripartite alliance is formed of the African National Congress (ANC), the South African Communist Party (SACP) and the Congress of South African Trade Unions (COSATU).
7. The top slice is removed before the national revenue is divided up among the provinces, but is disbursed as earmarked funds to provinces.
8. Diflucan is the brand name of the drug fluconazole, manufactured by Pfizer. This drug is required for life-threatening fungal infections common in people with HIV/AIDS, and was the target of initial campaigning for price reductions by the Treatment Action Campaign.
9. Extremely high rates of HIV infection (similar to that being found in Southern Africa) were documented in the gay communities of San Francisco and New York in the 1980s.
10. The anti-apartheid political mobilisation within South Africa.
11. The organisations included the National Medical and Dental Association (NAMDA), the National Education Health and Allied Worker's Union (NEHAWU), the South African Health Workers Congress (SAHWCO), and the Organisation of Appropriate Social Services in South Africa (OASSSA).
12. Specifically, the Trade Related Agreements on Intellectual Property Rights (TRIPS)
13. See for example, MSF statement on new UNAIDS Proposal, 12 May 2000 in which it states "Medicins Sans Frontieres greets with scepticism today's announcement by UNAIDS of a "New Public/Private Sector Effort." "
14. IAVI brings together representatives of international health agencies (UNAIDS, World Bank), the pharmaceutical industry, big business and biomedical researchers. IAVI recently received a large grant from the Bill and Melinda Gates Foundation. William Makgoba, President of the SA MRC is the only person on the board of Directors of IAVI who is based outside of the G8 countries. The research team of IAVI includes two South Africans.
15. A South African high court judge who publicly declared his HIV positive status, and has actively called for access to anti-retrovirals in the South.

16. Individuals who have taken public positions against Mbeki's stance on AIDS include William Makgoba, President of the MRC, and Mamphele Ramphele, former Vice-Chancellor of the University of Cape Town.
17. In a media poll conducted in June 2000, 45.5 per cent of respondents believed that the President Mbeki's intervention on the link between HIV and AIDS was positive (*Media Beat* 12 June 2000).

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