

The price of denial

For the last five years, a great deal of controversy has surrounded aspects of the South African government's response to HIV and AIDS. In the keynote article that follows, **Mark Heywood** attempts to document and explain South African President Thabo Mbeki's association with 'AIDS denialism' and the response of the Treatment Action Campaign (TAC). He argues that 'AIDS denialism' was a shift away from the ANC's own policy on HIV, and that it has impacted adversely on the implementation of a national AIDS policy that, on paper at least, is one of the best in the world.

You have to respond to a catastrophe in a way that recognises that you are facing a catastrophe. And here we are talking about people – it is not the death of animal stock or something like that, but people. Millions and millions of people (President Thabo Mbeki, Remarks at the First Meeting of the Presidential Advisory Panel on AIDS, 6 May 2000)

History may judge us, the present South Africans, to have collaborated in the greatest genocide of our time by the types of choices – political or scientific – we make in relation to this HIV/AIDS epidemic (M W Makgoba, Medical Research Council President, 2001)

Introduction

Since the early days of the AIDS epidemic, great emphasis has been placed on the importance of partnerships between governments and civil society, and on the involvement of people living with HIV/AIDS in planning and implementing responses to HIV. Indeed, the notion of partnership has become so entrenched that it is forgotten that the origins of this sacred principle lie in the reluctance of governments in the 1980s to include civil society in the response to HIV/AIDS. Partnerships with government were demanded, not offered, and were necessary because governments often responded to HIV in ways that reflected their own prejudices and ignorance. Unfortunately, twenty years after the first cases of HIV were reported, we tend to gloss over the fact that whilst partnerships are now accepted in policy, their practice remains far from perfect. The short articles from Zambia and Zimbabwe that are included in this journal illustrate that in most of the countries of the Southern African Development Community (SADC), partnerships against AIDS exist more on paper than in practice, and that as a rule governments continue to respond to this crisis in ways that they determine, rather than through collective agreement.

This is also the case in South Africa where, despite the formal existence of a 'Partnership against AIDS' since 1998, relations between government and civil society have been characterised by a long and continuing period of conflict and fracture. This article examines the causes of conflict over AIDS policy in South Africa by looking at the history of government-civil society relations through two interwoven responses: those of the Treatment Action Campaign (TAC) and of the African National Congress (ANC). It suggests that while the basis for a partnership between civil society and government was firmly established with the ANC before it became the government in 1994, that

differences over a policy on AIDS treatment, and in particular the embracing of AIDS denialism by part of the leadership of the ANC in 1999, undermined this collaboration and led to a prolonged conflict over AIDS policy. After TAC was founded in December 1998, the unanticipated need to confront political denialism about HIV had as its consequence an unnecessary conflict over policies, such as a National HIV/AIDS Treatment Plan (NTP), which should have united – rather than divided – civil society and government. This conflict was so bitter that even after government succumbed to the popular demand for a treatment policy and introduced a Treatment Plan in November 2003, a genuine partnership remains elusive.

From collaboration to conflict: Responses to HIV in the mid-1990s

The tenth year of South Africa's democracy is the twenty-third year since the first AIDS case was noted in medical journals. Unfortunately, however, HIV has always been ahead of attempts to contain it. In *Towards a Ten Year Review*, published in early 2004 by the Presidency of the South African Government, it is recorded that 'the prevalence of HIV/AIDS as estimated from public antenatal clinics shows an increase from 0.7 per cent in 1990 to 26.5 per cent in 2002' (Department of Health, 2002, 2003). What is not noted is the rapid increase in HIV-related deaths. In April 2004, the *SA Medical Journal* reported that between 1997 and 2003 adult mortality had undergone a 'real increase of more than 40 per cent' (Bradshaw *et al*, 2004:278-279). Thus, by 2004 the HIV/AIDS epidemic in South Africa has emerged as one of the greatest threats to post-apartheid reconstruction and development.

The *Review* lists 'addressing HIV/AIDS and other emerging diseases' as one of the key social challenges for the next decade' (GCIS, 2003:114). However, this conclusion aside, it largely overlooks the impact that HIV has had on the indicators of human development in South Africa's first decade of democracy. This itself is an illustration of political denial about HIV and of how the post-apartheid transition and the drama of political and social reconstruction has been accompanied by attempts to ignore, hide and marginalise the advance of the HIV/AIDS epidemic.

The *Review's* non-engagement with HIV is an obvious omission which is puzzling when we recall that in the years just before South Africa's democracy the threat of HIV was fully appreciated by the ANC. The ANC's 1994 *National Health Plan for South Africa*, for example, recorded that:

Forecasts to the year 2000 predict that there will be between 4 and 7 million HIV-positive cases, with about 60 per cent of total deaths due to AIDS, if HIV prevention and control measures *remain unaddressed*. Similarly, *credible* predictions indicate that by the year 2005, between 18 per cent and 24 per cent of the adult population will be infected with HIV, and that the cumulative death toll will be 2.3 million, and that there will be about 1.5 million orphans (ANC, 1994:17 (author's emphasis)).

In recognition of this challenge the agenda on prevention of HIV/AIDS was fashioned with the support and leadership of the ANC who had declared that it was 'mandatory to define prevention and control interventions plus comprehensive care for those already infected, within the context of the Bill of Rights' (ANC, 1994:27). To this end, a partnership known as the National AIDS Convention of South Africa (NACOSA) included ANC leaders such as Dr Manto Tshabalala-Msimang and Dr Nkosazana Zuma. NACOSA drafted a far-reaching National AIDS Plan which was speedily adopted as the policy of the Government of National Unity in July 1994 (NACOSA, 1994).

In the early 1990s the ANC also worked closely with the first non-governmental organisations (NGOs) that emerged to tackle the HIV epidemic. The most important of these were the National Progressive Primary Health Care Network (NPPHCN), the AIDS Consortium, the AIDS Law Project and from 1995 the National Association of People Living with HIV/AIDS (NAPWA). These organisations pioneered a response to HIV based on human rights, non-discrimination and dignity. They worked closely with the government-in-waiting and launched successful campaigns for a Charter on HIV/AIDS and Human Rights (1992), which was endorsed by the ANC (NHP:28); a Code of Good Conduct on HIV/AIDS in the Workplace, which was made government policy in 1998 and adopted by the Department of Labour in 2000; and for an end to mandatory pre-employment HIV testing in public and private sector employment, an approach that was adopted by Cabinet in 1997 (except in the South African National Defence Force).

However, when the ANC became the government several factors began to suggest an emerging divide between civil society and government. One was unease at the vacuum in political leadership as, under the presidency of Nelson Mandela, an immense array of other priorities, but also conservatism and traditional fears of talking about sex led to what Mandela later admitted was a failure to prioritise HIV prevention.¹

¹ In an interview with the BBC in 2003 Nelson Mandela admitted that in the 1994 election 'I wanted to win and I didn't talk about AIDS' and that once he was President he 'had not time to concentrate on the issue.'

The other was that the NACOSA plan, reflecting the period of its genesis, concentrated mainly on strategies for HIV prevention and palliation. However, after the benefits of using antiretroviral drugs were reported in the United States in 1996² many people began to call for an expanded policy that would also seek to keep alive those already infected with HIV.

As effective treatment for HIV became a reality in the United States and Europe, it became obvious that one of the greatest challenges facing the non-governmental sector was to launch a campaign to secure from government a policy and plan that recognised the right to treatment. The start of the presidency of Thabo Mbeki in 1999 marked the transition between the periods of partnership and conflict. Political ambivalence about treatment, and soon about HIV itself, led to a realisation among several leaders in the non-governmental sector that it would be necessary to build a social response to the HIV epidemic that would be characterised by the clamorous and insistent voices of large numbers of people directly affected by HIV/AIDS. It was recognised that catalysing a broader response to HIV would be inhibited by the *modus operandi* that had enveloped many NGOs working with HIV/AIDS. Organisations that in the early 1990s had made a vital contribution to the policy framework had begun to act as affected people's intermediaries and were failing to create public empathy with HIV or to catalyse the involvement of the people most vulnerable to HIV in South Africa – the urban and rural poor. The response to HIV was being ghettoised in the comfort zones of the professional NGO sector, with leaders of NGOs falling prey to the eternal circuit of conferences and workshops, a malaise that has unfortunately overtaken much of the international response to HIV.

The decision to set up a Treatment Action Campaign was consciously intended to change this and to confront government's conservative approach to the right of access to treatment. Thus TAC, which was established on December 10th 1998 at a one-day fast held on the steps of St George's Cathedral in Cape Town, was originally conceptualised as a campaign to transform the lacklustre NAPWA into a mass movement of people with HIV. From the outset, TAC expanded the human rights discourse that the ANC had accepted was integral to effective HIV prevention³ to the demand for access to antiretroviral treatment for children and adults with AIDS, and people who volunteered for TAC made a 'Pledge

² See Hammer *et al*, in the *New England Journal of Medicine*, 1996 and 1997; the *Consensus Statement on ARV Treatment for AIDS in Poor Countries*, from Members of the Faculty and Staff of Harvard University, 2000.

³ The National AIDS Plan, for example, had a chapter on Law and Human Rights.

to save Lives' promising to 'use my anger, fear, knowledge, emotions and care to win affordable treatment and care for people with HIV/AIDS.'⁴

On January 21st 1999 an agreement was reached with NAPWA leaders that the treatment action campaign would be supplemented by an 'openness and acceptance' campaign. A campaign of unapologetic advocacy for the right to health and life was launched. However, within weeks tensions emerged over the NAPWA leadership's failure to mobilise people for demonstrations on March 21 to demand a national mother-to-child HIV prevention programme and to monitor the police investigation into the murder of Gugu Dlamini. This led to a war of words and shortly after to a physical parting of ways as NAPWA relocated its Johannesburg office to the University of Pretoria, out of reach of TAC activists.⁵

In 2004 the 'right to treatment' is hardly controversial. Major international donors, governments and the United Nations system itself have been converted by activist pressure to making commitments to prevention and treatment (UNAIDS, 2002). In the late 1990s, however, the prevailing wisdom – and one that was vigorously defended – was that treatment was too complex for individuals and/or health systems in the Third World, too expensive or that prevention was more cost-effective for 'scarce' donor dollars.

Thus TAC's initial focus was on raising awareness among people with HIV of treatments, campaigning for lower medicine prices, and advocating for the right to treatment using antiretroviral drugs.

Reflecting the hitherto unexpressed need for treatment, TAC quickly began to emerge as a community-based response to HIV. It attracted many more people with HIV who were poor and black into activism. The social significance of this is often missed because of the media focus on individuals such as TAC's founder and chairperson Zackie Achmat. Achmat played an inspired and inspiring leadership role but the reality was that the campaign for the right to treatment engaged a diverse new group of individual leaders such as Siphon Mthati, Nonkosi Khumalo, Pholokgolo Ramothwala, Mandla Majola, Theodora Steele, Thabo Cele, Desmond Mpofu, Thembeke Majali, Nathan Geffen, Sharon

⁴ 'TAC Pledge to Save Lives', TAC Archive.

⁵ See TAC archives: Z. Achmat, letter to NAPWA Director, 30 March 1999; Z. Achmat, Statement on Who Should Lead NAPWA; Z. Achmat, letter calling for Independent Public Inquiry into NAPWA, 24 June 1999; Z. Achmat, Open letter to Mary Crewe on HIV/AIDS careism, 28 June 1999; M. Heywood *et al*, AF-AIDS posting re Charges Dropped in Gugu Dlamini Killing, 27 August 1999.

Ekambaram, Sarah Hlalele, Christopher Moraka, Herman Reuters and many others. Thousands of individuals, many with no prior involvement in politics or AIDS, were mobilised and began to mobilise others in demonstrations and community activities. This was a sea-change in AIDS activism that became crucial in giving TAC the social weight needed to confront multi-national pharmaceutical companies, and later South African government intransigence and delay.

But while the probability that this new approach to activism would cause conflict within the NGO sector was foreseen, it was not anticipated that the most intransigent opponent of a treatment campaign would become the leadership of the ANC. In 1998 there was no reason to suspect that pseudo-scientific opinions about HIV would be embraced by some ANC leaders and intrude adversely upon government policy. Rather, the leaders of TAC believed that once the evidence of the efficacy of antiretroviral drugs had been marshalled and their prices reduced then an extension of government policy to include the provision of treatment would logically follow.

Thus it was that at the funeral of Simon Nkoli⁶ in early December 1998, in a speech from the church pulpit, Zackie Achmat appealed directly to ANC leader Mosiuoa Lekota, then Chairperson of the National Council of Provinces, to persuade government to join in a partnership to save the lives of people with AIDS.⁷

The nature of denial

Denial about HIV is not unique to South Africa. Denial was first manifested by the Reagan government in the United States. It has subsequently been seen in India, China, Russia and many other countries. In all of these countries it has pitted people with HIV against their governments because it has entrenched the prejudice and stigma surrounding HIV, together with people's fear of AIDS. From the first cases of AIDS in the early 1980s, affected people had to battle government denial to get their health and social needs recognised and attended to. This is evident in the slogan 'Silence = Death', popularised by the AIDS Coalition To Unleash Power (ACT-UP), one of the first AIDS activist organisations in the USA, and in the angry essays of people like Larry Kramer, who in

⁶ Simon Nkoli was a gay man who died of AIDS. During his life he was an ANC and community leader and latterly the founder of one of the first organisations to deal openly with homosexuality among African gay men and later with HIV infection. More information about Nkoli can be obtained at www.gala.wits.ac.za

⁷ *Patient Abuse, TAC's struggle for Treatment Access*, 2001, produced by Community Health Media Trust.

the early 1980s shattered polite silences about HIV with newspaper articles such as one famously titled '*What are you doing to save my fucking life?*' (Kramer, 1997).

Activists in developed countries were the first to break the silence. But in developing countries this silence is even more oppressive because it is mixed up with the pathologies of poverty and deprivation: gender inequality, illiteracy, violence against women, acquiescence to undemocratic powers of chiefs and unelected rulers. Further, people whose poverty often means that they are already beset by disease make an easier accommodation with a new disease, even HIV. For the poor, the aetiology of a disease may be irrelevant if the symptoms and causes are much the same.

South Africa, although more economically developed than most countries in Africa, was no exception. For a community-based AIDS activist movement to emerge and successfully demand access to treatment it was necessary for it also to confront the multi-layered problems of stigma and denial that exist first and foremost in communities, and are much more suffocating and dangerous to the poor than to the middle class.

For many people affected by HIV, denial is a natural response to news of an HIV diagnosis, just as it may be to diagnosis of any other life-threatening illness. Where people do not receive counselling, information and support, denial may persist over many years. Similarly, fear and ignorance of an epidemic may cause whole communities to respond in a manner that tries to deny the existence or cause of an epidemic. The murder of Gugu Dlamini was arguably an act of denial, illustrating that it was inextricably mixed up with stigma, which has at its core the desire to locate blame in somebody else.

Tackling stigma – which is itself an expression of denial – was, and remains, a great challenge. In this respect simple devices such as the 'HIV positive' T-shirt proved to have remarkable power in confronting people's attitudes about HIV at the same time as emerging as a badge of the activist community and signifying both solidarity between the living and tribute to those who have died. The first 'HIV positive' T-shirt carried the picture of murdered NAPWA activist Gugu Dlamini and the slogan 'Never Again'. Since then there have been numerous further 'editions'.

But a point many commentators miss is that fighting stigma is not just about removing prejudice – it is about putting something in its place. Expanding access to real information about HIV and its treatment to poor communities – rather than just the 'ABCs' of HIV prevention – equips people to make decisions. Thus it was that a campaign

for access to treatment came to generate an organisation that, while never intending to clash with government, could not avoid conflict in the face of the unexpected change in approach to HIV initiated by President Mbeki in late 1999.

Individual and psycho-social denial about HIV must be distinguished from the various manifestations of political denial that have characterised responses to HIV. As already explained, governmental denial about the HIV epidemic is an international phenomenon, although its causes and duration have differed from country to country. But whereas in other countries AIDS denialism gradually evaporated in the face of growing information about HIV or the demands of people with HIV, in South Africa it resisted attack.

The ANC and AIDS: From determination to denial

The manner in which President Thabo Mbeki has encouraged and defended AIDS denialism has been widely examined.⁸ In his defence, it is true that Mbeki has not expressly or publicly 'ever denied a link between HIV and AIDS,'⁹ but he has also never publicly affirmed that HIV does cause AIDS. Instead he has left a paper trail of his questions about HIV and hints about his sympathies with the denialists, the impact of which can be traced through what was not done by his government as well as what was questioned and resisted.

In 1998 Mbeki referred to the 'escalating HIV/AIDS pandemic' as a 'pressing crisis'. Therefore, what is not properly understood is why and how such a radical shift in his own views and from the policy position adopted by the ANC national health plan took place.

As already illustrated, the question of how to control the HIV/AIDS epidemic genuinely concerned the ANC long before Mbeki's presidency. The ANC was at the forefront of post-1990 efforts to formulate an appropriate response to HIV. It helped create the

⁸ See M. Heywood, Preventing Mother to Child HIV Transmission in South Africa: Background, Strategies and Outcomes of the TAC case against the Minister of Health, *SA Journal on Human Rights*, Vol. 19, Part 2, 2003; M. Mbali, 'Mbeki's Denialism and the Ghosts of Apartheid and Colonialism for Post-apartheid policy making'; M. Schoofs, 'Flirting with Pseudo-Science', *Village Voice*, March 15-21, 2000.

⁹ Government and ANC spokespersons have been at pains to stress this point. See 'Building a Monument to Intolerance', Release from Mr Parks Mankahlana, Head of Communications, President Mbeki's Office, 23 March 2000; 'Response to Enquiries and Comments on HIV/AIDS', Statement Issued on Behalf of the Government 14 September 2000.

National AIDS Convention of South Africa (NACOSA). The challenge of HIV/AIDS was mentioned in both the Reconstruction and Development Programme (RDP) (ANC, 1994:48) and the ANC's National Health Plan for South Africa (ANC, 1994:17). In 1997, the ANC's 50th National Congress passed a resolution that noted that HIV/AIDS would 'massively impact on the economy, will impact socially with more orphans and the loss of breadwinners, and on the health service with additional new users'. The resolution ordered that the HIV prevention campaign be led by the President of our organisation who must direct the NEC, Branches, the Youth League, the Women's League throughout our Provinces to place the campaign against Aids on their day to day agendas.¹⁰

Despite these commitments, however, the ANC government's response to HIV/AIDS was one of the first issues where it faced a serious challenge from civil society. In 1996, for example, there was a controversy over spending R14 million on the AIDS play 'Sarafina'. Then in 1997 a group of 'AIDS researchers' were assisted by Mbeki to have an audience with the Cabinet to present their 'research findings' on an AIDS drug they claimed to have developed called 'Virodene'. The 'researchers' were endorsed (or at least not blocked) by the Cabinet and went on to announce their discovery in a misleading blaze of publicity (Miracle AIDS Cure Hits the South African press, *British Medical Journal*, 1997, 314:450).¹¹

Non-governmental organisations, particularly the AIDS Consortium, and the Medicines Control Council (MCC), dismissed Virodene and denounced the transgression of ethics by the researchers. The MCC conducted an investigation and then refused to grant permission for any further research on human subjects. In response, Mbeki defended the research in the ANC's newspaper *Mayibuye*, and accused the MCC of using its 'powers to decide who shall live or die' to deny 'dying AIDS sufferers the possibility of 'mercy treatment' to which they are morally entitled.'¹²

¹⁰ Resolution on HIV/AIDS of the 50th National Congress of the ANC, available at www.anc.org.za.

¹¹ This article reported that 'South Africans had been informed of the 'miracle' find in huge front page splashes and long inserts on television. The Johannesburg daily newspaper, *The Star*, used most of its front page, with elaborate colour illustrations of the virus and the new drug Virodene P058, to inform its readers of its discovery.'

¹² T. Mbeki, 'ANC has no financial stake in Virodene', *Mayibuye*, March 1998. Subsequent research by investigative journalists has suggested that the ANC's interest in Virodene was not purely publicly minded. See *Mail and Guardian*, July 5 2002, 'The ANC's Virodene backers: The ANC secretly arranged millions of Rands in funding for Virodene.'

A year later, in 1999, Mbeki discovered the thesis of the AIDS denialists, apparently while working on the internet. Ironically, the conflict over Virodene appears to have catalysed Mbeki's further inquiry into HIV, and armed with a set of pseudo-scientific arguments he appears to have gone on a campaign within government and the ANC to advertise their beliefs and to then insist that their contentions be used to test the prevailing scientific wisdom about HIV.

It was a tragic and bizarre coincidence that the emergence of TAC, whose first public campaign was to call for a national programme using the antiretroviral drug AZT to reduce the risk of mother-to-child HIV transmission (PMTCT) coincided roughly with the advent of a period of AIDS denialism in the South African government. TAC launched its PMTCT campaign with a postcard campaign imploring President Mbeki to provide 'AZT/NVP to pregnant women with HIV' and a 'Fast to Save Lives' on March 21st 1999, Human Rights Day. The first public signal that Mbeki gave of his interest in the denialists came in direct response to the growing publicity around the campaign, when he questioned the safety of AZT in a speech in Parliament in October 1999.¹³ Then, at the end of 1999 the MCC was requested by the Minister of Health to review the safety of AZT before its use could be permitted for the prevention of mother to child HIV transmission. Given that there was no new evidence about AZT, other than Mbeki's views, this seemed like a punitive tit-for-tat for the MCC's refusal to sanction further research of Virodene. To add fuel to the fire, Mbeki's attacks on AZT were heralded by local AIDS denialists such as Antony Brink, who published a book about AZT that was dedicated to Mbeki 'for his sterling moral and political leadership in the AZT controversy in South Africa' and to the Minister of Health for 'equal integrity and political courage'.¹⁴ The growing number of children being infected with HIV meant that this was bound to be an emotive issue, and one that went to the core of the loss experienced directly by those TAC activists whose young children had died of AIDS.

At this point, the path of conflict between the government and TAC was not yet fixed. In February 2000, for example, TAC addressed a meeting of the ANC's Health Committee to explain its 'defiance campaign' to reduce the price of Diflucan, Pfizer's brand name for the anti-fungal medicine, Fluconazole. At the end of the meeting, the validity of the denialist thesis was raised by a member of the committee. TAC's response was to warn

¹³ Debates of the National Assembly, in *Hansard* 16 November 1999.

¹⁴ A. Brink, *Debating AZT, Mbeki and the AIDS Drug Controversy*, 2000, Dedication and Acknowledgements.

that public questioning by the ANC leadership of the mainstream science on HIV/AIDS would lead to confusion that could damage the government's own HIV prevention programmes.¹⁵ It was pointed out that denial about HIV was already a social phenomenon and that this would harden it.

The reaction of several committee members to this was that TAC was guilty of a 'Stalinist' desire to suppress debate and inquiry – something the ANC had always encouraged. In response it was pointed out that while scientists continue their searches, most modern governments opt to build policy on prevailing wisdoms and best evidence, rather than risk causing paralysis in any area of governance. In many sciences, including economics, for example, there are still knowledge gaps. It would be a reversion to Stalinism if either TAC or the government acted as if there were no longer debates in the field of medicine. In the context of a life-threatening global epidemic, already clothed in stigma, denialism and fear, and the constitutional obligation to protect life, there was a responsibility to ensure that this 'debate' did not paralyse the national response to HIV. This, unfortunately, was not what happened.

Throughout 2000, Mbeki made his oblique questions increasingly public in a series of letters, interviews and speeches. Actions such as the establishment of the Presidential AIDS Advisory Panel, which included many denialists, were seen by civil society and the scientific community as a calculated affront to the International AIDS Conference, held in Durban in July. Tempers were raised when Presidential spokesperson Parks Mankahlana responded to the Durban Declaration by saying it belonged 'in the dustbin', and right-wing AIDS denialists, such as Peter Duesberg, were glorified as heretics cut from the same cloth as Galileo (Mbeki, 2000).¹⁶

¹⁵ It is important to note that President Mbeki was given exactly the same advice by Dr W. M. Makgoba, at the time President of the Medical Research Council. Makgoba told the Helen Suzman Foundation that 'my own view is that this process should never have been public. I am a scientist. I have been convinced by the evidence. There are politicians who are facing major policy changes and want to explore all possibilities. Indeed, I have to confess the President did consult me early in this matter. I told him what I've always told him. But the president felt it was necessary to consult these other people to see whether together we could resolve these differences.' In *Focus*, 18, 2000.

¹⁶ In a 'Letter to world leaders on AIDS in Africa', (April 3, 2000) Mbeki wrote: 'The day may not be far off when we will, once again, see books burnt and their authors immolated by fire by those who believe they have a duty to conduct a holy crusade against the infidels. It is most strange that all of us seem ready to serve the cause of fanatics by deciding to stand and wait. It may be that these comments are extravagant. If they are, it is because in the very recent past, we had to fix our own eyes on the very face of tyranny.' See www.virusmyth.net/aids/news/lettermbeki.htm.

In a different political conjuncture, the private views of a leader of government on an issue such as HIV/AIDS might have had less of an impact on his party. But less than six years after the advent of democracy in South Africa, and in the context of a strong conviction within the ANC that there are political and economic forces that still seek to undermine the ANC government, the opinions of the party leader held great sway. In addition, Mbeki clothed the 'scientific' views of the denialists in a political analysis of neo-colonialism, disease and economy. This meant that HIV began to be 'understood' by a powerful leadership group in the ANC through the prism of half-truths that seemed convincing precisely because they are half true!¹⁷

Pharmaceutical companies that manufacture antiretroviral drugs were deemed to be part of a capitalist conspiracy to undermine the ANC government – a view that held greater sway when in 1998 the Pharmaceutical Manufacturers Association (PMA) launched a legal action against the Medicines and Related Substances Amendment Act, legislation that was intended to make medicines more affordable. It was hinted that HIV might even be an imaginary epidemic invented by pharmaceutical companies and neo-colonialists to make profits and to continue to dent Africa's view of itself.¹⁸ The epidemiology of the African HIV epidemic, explained by the World Health Organization, was claimed to be a modern manifestation of old stereotypes of African people as 'a diseased and depraved people ... perishing from self-inflicted disease', 'germ carriers, and human beings of a lower order that cannot subject its passions to reason.'¹⁹ But this time the aim of the racists was to dehumanise the African during a time of renaissance. Opposition to questioning by Mbeki was portrayed variously as fanaticism or as an attempt by patronising 'friends of the African' to silence the cheeky native.

Based on these contentions, it did not require a great leap in logic to depict treatment activists and mainstream scientists as agents of an 'omnipotent apparatus' (imperialism or the pharmaceutical companies). Thus, in September 2000 it is alleged that Mbeki

¹⁷ Among the ANC leaders who firmly aligned themselves with Mbeki are Dr E. Pahad, the Minister in the Office of the Presidency; the Minister of Health; the head of the Presidency, Smuts Ngonyama; and the late Peter Mokaba.

¹⁸ 'It is precisely this scare-mongering that is condemning millions of our own people to ill-health, disability and death because of a refusal to recognize the critical importance of the diseases of poverty and other illnesses that afflict our people, including STDs. This is done to sustain a massive political commercial campaign to promote antiretroviral drugs.' *Castro Hlongwane, Caravans, Cats, Geese, Foot and Mouth and Statistics - HIV/AIDS and the Struggle for the Humanisation of the African*, January 2 2002 at p. 15.

¹⁹ T. Mbeki, 'Z. K. Matthews Memorial lecture', Fort Hare University, October 12th 2001.

told the ANC parliamentary caucus that TAC was a front for drug companies, and had successfully 'infiltrated' the trade union movement, an allegation which the trade unions rejected.²⁰ But sadly, this type of reasoning found an echo inside and outside of the ANC. For example, in July 2000, respected journalist Mathatha Tsedu, then acting editor of *The Star*, defended Mbeki by writing that 'to understand why Mbeki is being so violently attacked... one has to look at the profiteers from this mess. Drug companies mounted a slick public relations exercise, backed by rent-a-demo props who thrust drugs forward as the solution.'

Tsedu's views in turn found further support in the higher echelons of the ANC. Former Presidential spokesperson Parks Mankahlana, for example, responded to the criticism of Mbeki with the following warning:

HIV/AIDS is not going to succumb to the machinations of the profiteering pharmaceuticals and their propagandists. Like the marauders of the military industrial complex, the profit takers who are benefiting from the scourge of HIV/AIDS will disappear to the affluent beaches of the world to enjoy the wealth accumulated from humankind ravaged by a dreaded disease. And we shall continue to die from AIDS.²¹

The mis-education of the ANC reached its zenith in early 2002 with the circulation within the ANC of a document titled *Castro Hlongwane, Caravans, Cats, Geese, Foot and Mouth and Statistics: HIV/AIDS and the Struggle for the Humanisation of the African*. This document, which one journalist claimed was penned by Mbeki (H. Barrell, *Would the Real AIDS Dissident Please Declare Himself*, *Mail & Guardian*, April 19 2002), was not officially sanctioned by the ANC, but neither was it discredited. The document is a hodge-podge of conspiracy theory and political theory, and shows why rational engagement with real issues of HIV prevention and treatment, such as the call for a national treatment plan, had become so difficult.

Tragically therefore, although the ANC and Mbeki deny it, the privately-held opinions of the leader of the party did begin (and continued for several years) to govern the

²⁰ See in particular an article in *The Educators' Voice*, newspaper of the South African Democratic Teachers Union (SADTU), Vol. 4:8, October 2000, titled 'Sorry, Mr President, We Cannot Infiltrate Ourselves'.

²¹ 'Just Stick to What Mbeki Said'. Press release from Mr Parks Mankahlana, Head of Communications, President Mbeki's Office, 23 March 2000. Mankahlana died in October 2000, reportedly of AIDS.

actions of the ANC and the government, eroding the official policies of both. One of the persons faced with the greatest difficulty in articulating this shift in approach to HIV has been the Minister of Health, Dr Manto Tshabalala-Msimang. Msimang comes from the mainstream approach to HIV. In 1972 she had founded the ANC's health department in exile. When she returned to South Africa she was deeply involved in repositioning the country and the ANC to address the AIDS epidemic as a priority. Before joining the government, for example, she worked for the National Progressive Primary Health Care Network. When Tshabalala-Msimang was appointed Minister of Health in 1999 she seemed to have prioritised rebuilding relationships with civil society and fashioning a more purposeful partnership against AIDS, meeting several times with the TAC and initially establishing a close working relationship.

However, the delay in initiating a programme to prevent mother-to-child HIV transmission in the face of convincing scientific evidence of the efficacy of ARVs for this purpose led to the breakdown of this partnership. In the face of the President's suddenly discovered opposition to the use of ARVs, Tshabalala-Msimang had to cut a new policy on HIV – one which was diametrically different to the policy direction that was emerging before her tenure. For example, when the results of the Bangkok study on the efficacy of a short course of antiretroviral therapy to prevent MTCT were announced in 1998, the reproductive health director of the Department of Health, Dr Eddie Mahlangu, had said: 'this is exciting news for the Department of Health because for the first time there is a possibility of something fairly affordable that can be used to prevent babies being infected' (*The Citizen*, 20 February 1998). In early 1999, Dr Nkosazana Zuma, the ANC's first Minister of Health, supported the introduction of an MTCT programme. When she had met with TAC on 30 April, 1999 she endorsed the campaign to lower the price of AZT and at this point it appeared that the major barrier to implementation was the cost of medicines.

However, under the new Minister of Health it would be a further four years before the programme was instituted – and then only after a sustained mobilisation by TAC against the government that culminated in an instruction from the Constitutional Court in the TAC case.²² Perhaps one of the gravest consequences of AIDS denialism has been the integrity of the Ministry of Health, as it has sought to defend and give a rationale to a politics about AIDS that impedes a proper response.

²² *Minister of Health v TAC* (no. 2) 2002 (5) SA 721 (CC). The background to this case is fully described in 'Preventing Mother To Child HIV Transmission in South Africa: Background, Strategies and Outcomes of the TAC Case Against the Minister of Health', *South African Journal on Human Rights*.

Refuting the denialists

TAC unintentionally became the largest civil society organisation in South Africa campaigning on HIV/AIDS, and also the only organisation that was prepared to robustly and unapologetically challenge AIDS denialism, thus souring relations between TAC, the ANC and the Ministry of Health. TAC's protest was joined by a handful of individuals such as W. M. Makgoba, President of the Medical Research Council, and judge Edwin Cameron, both of whom were prepared to publicly warn of the consequences of this shift in policy. Cameron compared AIDS denialism with holocaust denialism²³ while Makgoba described the approach as potentially genocidal (Makgoba, 2002).

It is plausible that the stand of individuals such as Makgoba and Cameron, together with the clamour created by the TAC and COSATU, may have encouraged Nelson Mandela to begin to demand that government lead a proper response to the HIV/AIDS epidemic. In July 2000, in his closing speech to the 13th International AIDS Conference in Durban, Mandela, while not coming out in direct opposition to Mbeki, for the first time placed himself in sharp relief to his successor. Speaking on behalf of 'the ordinary people of the continent and the world – and particularly the poor who, on our continent, will again carry a disproportionate burden of this scourge' Mandela requested:

that the dispute about the primacy of politics or science be put on the backburner and that we proceed to address the needs and concerns of those suffering and dying. And this can only be done in partnership.

Specifically, Mandela called for 'bold initiatives to prevent new infections, large-scale actions to prevent mother-to-child transmission and an international effort of searching for appropriate vaccines' (Mandela, 2000).

Aside from Mandela, the opposition that existed within the ANC to the re-direction of AIDS policy into the terrain of AIDS denial seems to have been minimal. A great deal of anger was privately expressed, but few officials were prepared to openly challenge the leadership's position. One of these was Pregs Govender, an ANC member of parliament and Chairperson of Parliament's Joint Monitoring Committee on the Improvement of the Quality of Life and Status of Women.

²³ Edwin Cameron was interviewed by the *Mail & Guardian*, reporting on a lecture later published in the *South African Law Journal*.

In 2001, the committee conducted extensive public hearings to examine the impact of HIV on women and girls. The TAC made written and oral submissions to this committee. On completion of the hearings, the committee made recommendations that contained no prevarication on whether HIV caused AIDS: they stated clearly that, under South African law, women had a right to treatment and to antiretroviral drugs to reduce the risk of MTCT and HIV infection after rape.²⁴ According to Govender, the report was welcomed overwhelmingly by members of the ANC caucus in Parliament, but blocked by the ANC leadership and not discussed until March 2002. Reflecting on the role of MPs in the HIV/AIDS 'debate' Govender claimed that the tradition of 'collective decision-taking' had evolved into 'group-think':

The tradition of the collective and the tradition of open debate in the ANC has been a proud and honourable tradition. There have, however, always been those who have attempted to reduce it to group-think. The collective and group-think are polar opposites. The collective is a celebration of the wisdom that resides within each one in the collective. It allows for vigorous and fearless debate and dialogue on the most difficult issues. It knows it is important to respect the experience and skills of each one in the collective. Group-think is the celebration of the individual above the collective, in its naïve and unquestioning acceptance of the leader as infallible (Govender, 2004).

Between 2000 and 2002, the vociferousness of TAC on the need for a comprehensive response that included treatment contrasted sharply with the defensiveness of the ANC. Under public pressure Mbeki retired from the forefront of the 'debate', and formally delegated responsibility for HIV/AIDS to Deputy President Zuma. The denialist baton was passed to ANC leaders such as Peter Mokaba, Smuts Ngonyama and Ngoako Ramathlodi, who periodically continued to attack mainstream views and treatment

²⁴ *How Best Can South Africa Address the Horrific Impact of HIV/AIDS on Women and Girls? Report of the Joint Monitoring Committee on the Improvement of the Quality of Life and Status of Women.* November 2001. On MTCT: 'The committee concluded on the basis of the range of evidence presented to it that, in relation to MTCT, the benefits outweigh the risk and it is affordable. It can end the 'unnecessary loss of life' referred to in the Health Committee's report' (p. 11). On PEP, the JMC report recommended: 'An expert committee needs to be urgently convened by Government to examine recommendations for best practice and develop a guideline for use of ARVs as post-exposure prophylaxis for rape. The Committee believes outrage at the horror of these rapes has to be converted into action to prevent the additional tragedy of the rape survivor (baby, child or woman) contracting HIV/AIDS' (p. 12).

activists and used *ANC Today* to air denialist misinformation.²⁵ Unfortunately though, Mbeki's public silence on the subject now expressed as much as his questions, particularly as behind closed doors he seems to have continued his campaign.²⁶

In early 2002, Mandela once again publicly vented his frustration with the 'debate'. In March 2002 at a press conference attended by Jacob Zuma and Essop Pahad which, according to *The Star*, was intended 'to present a united front on HIV/AIDS', he called directly for people with AIDS to have access to antiretroviral treatment. Newspaper reports suggest that his comrades were 'taken by surprise' (*The Star* 5 March 2002).

Mandela's statements during this period were contradictory, sometimes claiming to be at one with the ANC on AIDS policy, and at other times obviously at odds. However, eventually Mandela's continued interventions led to a meeting of the ANC National Executive Committee (NEC) in March 2002 to discuss AIDS policy. In the lead-up to this meeting, allies of the President railed against Mandela's intervention. For example, an article by Thami Mazwai in *City Press* was titled 'Leave Mbeki to Rule!' and began:

Former President Nelson Mandela's intervention in the HIV/AIDS issue and in fact on several other issues concerning the government is not diplomatic. It is insensitive and undermines President Thabo Mbeki's government. Sir Ketumile Masire of Botswana left government and does not spend his time tutoring his successor, Festus Mogae, on how to run the country. If he does, it is within the confines of his office and that is not publicized. Likewise in the United States. Bill Clinton has left the White House and little is heard of him on issues of state.²⁷

²⁵ See *ANC Today*, Vol. 1, No. 13, April 20th 2001, for selective quotation of the United States ARV Guidelines, highlighting issues of toxicity and ignoring evidence of efficacy. See also *ANC Today*, Vol. 1 No. 17, May 2001, for misuse of an article about U.S. Food and Drug Administration (FDA) warnings about misleading advertisements for ARV drugs.

²⁶ On August 6 2001, for example, Mbeki wrote to the Minister of Health, urging an investigation of HIV and AIDS statistics on the grounds that 'the government has to respond to the objective reality of the health profile of our country and not what we or other people wish it to be or mistakenly assume it to be'. The letter is reproduced in full in *Business Day*, September 10, 2001. When the investigation called for by Mbeki was completed and published in December 2002 by Statistics South Africa, Mbeki largely overlooked it.

²⁷ *City Press*, 10 March 2002. The same article gave a further clue to the clique from which its ideas originated, when Mazwai questioned how the TAC 'which is leading the hysteria against the government, had full-page adverts in the national media about six weeks ago. Knowing what these adverts cost, where does this NGO get the fortune it spent on advertising and the legal battles against the government? Is it not that some major pharmaceutical companies are funding them?'

At the ANC NEC Mandela was rebuffed and rebuked. According to the *Mail and Guardian* (22 March 2002):

'AIDS dissidents such as Peter Mokaba gained the upper hand at the meeting. He was provided far more air-time than we were,' complained a member. Said another, 'It appeared as if he had the endorsement of the party leadership.'

The outcome of the NEC meeting was a statement of counter-attack, repeating the defensive and unconvincing mantra that the ANC worked from 'the assumption that HIV causes AIDS.' The statement took a hard line in relation to TAC's demands on MTCT prevention, and the recommendations of the JMC report. It stated that the use of Nevirapine 'remained a research question'; and that the efficacy of antiretrovirals for post-exposure prophylaxis (PEP) after rape was 'unproven'. It stated categorically that antiretroviral drugs 'could not be provided in the public health system because of prohibitive costs and the complexity of management with disastrous consequences in instances of non-compliance, which is quite common in managing such diseases as TB' (ANC, 2002).²⁸

In retrospect, however, Mandela's opposition and the pressure coming from TAC and other quarters, appears not only to have had an effect on the government's position, but to have been indispensable in achieving movement on a public commitment to treatment provision. On April 17 2002, a month after the NEC, the Cabinet unexpectedly issued a press statement on HIV/AIDS. For the first time this press statement made a commitment to 'work on a universal roll-out plan' to prevent mother-to-child HIV transmission; promised to develop a programme providing access to PEP for survivors of rape; and recognised that antiretroviral medicines 'could help improve the conditions of PWAs if administered at certain stages in the progression of the condition, in accordance with international standards.'²⁹ TAC immediately welcomed the statement but unfortunately this 'hand of hope' did not bear immediate fruit. It appears to have been more a sop to public pressure than a real commitment.

Although public questioning of the thesis that HIV causes AIDS subsided, ANC leaders and the Presidency seemed intent on continued denial of the extent of the epidemic,

²⁸ 'Lend a Caring Hand of Hope'. Statement of the Executive Committee of the ANC, 20 March 2002.

²⁹ Statement of Cabinet on HIV/AIDS, April 17th 2002.

perhaps thereby justifying to themselves the failure to take the measures which President Mbeki himself said are consonant with a catastrophe. Important research reports were held back if they contained unpalatable recommendations,³⁰ delayed if they showed a continued growth of the epidemic³¹ or disputed if they contained worrying projections.³²

In addition, the vilification and misrepresentation of the TAC continued. In April 2003, for example, an article by Khulekani Ntshangase, a spokesperson of the ANC Youth League (ANCYL), described TAC as 'just a harmless but very loud pressure group whose salaries are paid by Americans. This is a conglomeration of drug-dealers who serve as marketing agents of toxic drugs which are not even used where they come from, America.'³³ In August 2003, ANC supporters were being enjoined by the President to refuse to deal with treatment activists, demeaned as 'placard carriers', and commended for 'refusing to allow the never-ending search for scientific truth to be suffocated by self-serving beliefs' when raising questions about the antiretroviral drug Nevirapine.³⁴

This obviously created issues around which a conflict between TAC, expressing the sentiments of a broader and broader coalition of civil society, and the government continued through the courts (the judgment of the Constitutional Court in the TAC case was handed down in July 2002); through demonstrations (TAC launched its Civil

³⁰ 'Report from the National Scientific Consultative Forum on HIV/AIDS, Getting Scientific Knowledge into Policy, Turning Knowledge Gaps into Research', convened by the National Department of Health and Health Systems Trust, August 13-14, 2002. On the section of the report's Consensus Statement on antiretroviral treatment (p. 76) under Recommendations: 'There is an undeniable humanitarian and economic need to provide access to ARV treatment.' The report proposed setting up four 'intensive public sector ARV operational research sites' for the implementation of an ARV programme (p. 77).

³¹ Until 2001 the results of the annual antenatal survey of HIV prevalence among women attending public sector clinics, conducted each year in October and November, were usually made public in March/April the following year. In 2003 they were released in September.

³² Medical Research Council of South Africa, *The Impact of HIV/AIDS on Adult Mortality in South Africa*, September 2001. This report was held back by the Cabinet until it was eventually leaked. In the Preface, then President of the MRC, W.M. Makgoba, wrote: 'I sincerely hope the information in this report will be used to promote the culture of 'Breaking the Silence' around this silent killer of our nation.'

³³ 'Pagad and TAC - Two Sides of the Same Coin', *Sowetan*, April 22 2003.

³⁴ Letter from the President, 'A Hundred Flowers Under the African Sun', *ANC Today*, 1 August 2003. Later in his letter Mbeki writes: 'we must free ourselves of the 'friends' who populate our ranks, originating from the world of the rich, who come to us, perhaps dressed in jeans and T-shirts, as advisers and consultants, while we end up as the voice that gives popular legitimacy to decisions we neither made, nor intended to make, which our 'friends' made for us, taking advantage of an admission that perhaps we are not sufficiently educated.'

Disobedience Campaign in early 2003); and through ongoing public criticism of the tardiness of government policy. A genuine partnership remained elusive.

Repairing the damage

It is for these reasons that the campaign for treatment was often reactive to the ANC and the government. The effect of the denialist agenda – and the ANC's refusal to clear it off the public agenda – was to cause suspicions and mistrust that linger to this day.

In April 2004, in a pre-election interview with the *Mail and Guardian*, Sankie Mahanyele-Mthembu, the deputy secretary general of the ANC, was the first senior leader of the ANC to admit to a mistaken approach to HIV. Asked whether she felt that the party had been 'damaged by its handling of HIV/AIDS' she replied:

The debate in the ANC took place in the context of the entire world struggling to deal with the epidemic; it was a trial-and-error situation. The people understood this, there was no backlash on the ground.... I don't think being wrong on an issue necessarily damages an institution – people make mistakes and misjudge. The important thing is to say: 'We were wrong, now we must take the correct route' (*Mail and Guardian*, April 8-15 2004).

This concession, while welcomed, portrayed as a 'mistake' an approach that caused great loss of life and dignity, and derailed South Africa's attempt to contain the epidemic during a critical period.

The funeral of a TAC leader, Edward Mabunda, on 19 April 2003, was symbolic of the conflicts and contradictions 'the debate' created. Mabunda was a respected ANC leader in the Winterveld area. However, in the last years of his life the ANC had no internal space to admit his – or others' – HIV infection. Mabunda's last years of social activism therefore found expression through TAC. When in early 2003 Mabunda became ill with HIV-related illnesses, he had to travel 90 kilometres for medical attention at Johannesburg General Hospital, getting assistance from TAC leaders such as Pholokgolo Ramothwala.

The absence of 'a debate' in the ANC about the cause of his illness might have meant that he could have found medical and emotional support closer to home. Instead he died at the Johannesburg Hospital, visited in his last hours by leaders of TAC and

COSATU but, despite the publicity surrounding his illness, not the ANC. Nonetheless, the Winterveld ANC branch and local ANC councillors, including the Mayor, rushed to reclaim him in death. Attempts were made by the ANC to take control of his memorial service and funeral and to play down his HIV infection and his association with TAC. However, his mother and wife resisted this and the funeral was jointly organised by the ANC and TAC.

Mabunda's funeral, attended by over 1 000 people, was the first public funeral where an ANC leader was openly said to have died because of AIDS. It took place during the TAC Civil Disobedience Campaign and TAC's 'HIV-Positive' T-shirts, posters of the Minister of Health declaring 'Wanted for Failing to Stop 600 Deaths a Day' and posters of Mabunda proclaiming 'Why Civil Disobedience is Necessary' flew alongside ANC flags. ANC, COSATU and TAC leaders addressed the funeral service. Despite this formal rapprochement, after Mabunda's body was lowered into the grave, ANC Youth League members made threats of violence against TAC activists as they were leaving the township.

ANC Secretary General, Kgalema Motlanthe says the ANC does not regret the way it has handled the issue (*City Press*, 28th February 2004), but tragically, in the period of the ANC's 'mistake' over HIV/AIDS there must have been thousands of other ANC leaders – including perhaps even more than one Cabinet Minister – who died without disclosing their HIV infection to the party or their family or the public. AIDS denialism accentuated stigma. It reimposed silence on people during a time when openness could have been achieved. The reason there has been no 'backlash from the ground' was because many people were too ashamed, uncertain and stigmatised to organise it.

The politics of TAC

Despite having to confront what Edwin Cameron described as 'the dead hand of denial' the TAC has adopted a political strategy that always preferred collaboration with government rather than conflict. Throughout this protracted contest, the TAC responded first with research and rational argument, and resorted to litigation and protest only after this failed to bring about a change in policy. This sets TAC apart from other 'social movements' in South Africa (Friedman & Mottiar, 2004). Its campaigns have always been explicitly in pursuit of the realisation of constitutional rights to life, dignity and health care services. At times this has located it as a firm ally of government, and at other times as an opponent. In 2001, for example, TAC initiated and led large

international demonstrations to support the South African government against profiteering by pharmaceutical companies. Later in the year it mobilised national and international opinion against government policy on PMTCT.

As a result of this conflict over AIDS policy, the TAC has been inaccurately depicted as 'anti-government'. TAC does not question the underlying commitment of the ANC to better people's lives, and there is, in fact, sympathy and appreciation for the governance challenges of post-apartheid reconstruction. But an appreciation of the difficulties facing the government cannot justify silence regarding delays in social improvement or about policies, which have, in some cases, demonstrably worsened peoples' lives.³⁵ TAC and civil society allies such as COSATU insist that poor people do not give up on their right to expose their anger, pain, suffering and indignity while the reconstruction project takes its course. Paradoxically, to be quiescent in the interest of democratic nation-building undermines the essence of democracy, because it allows political leaders a sense of complacency. It also deepens the risk that, in what COSATU's leaders described in 2002 as 'the battle for the soul' of the ANC, those who seek to influence the ANC to protect or advance their own privilege can do so without opposition from a social counter-weight.

The history of Mozambique, Angola and many other countries that have sought to follow an independent political agenda, bear out the ANC's contention that the opponents of democracy come not only from within South Africa. Thus the notion of an 'omnipotent apparatus' is not wholly without substance. But these countries also illustrate the potential for an internal corruption, and how vital civil society (in whatever form) is in holding a party to its ideals.³⁶ Recent history demonstrates repeatedly that political leaders of developing countries often find themselves under sustained and immense pressure to adopt and implement political and economic policies that are devised by the International Monetary Fund in the interest of United States and local and international big business.

³⁵ In 1996, replacing the expansionist Reconstruction and Development Programme (RDP) with the fiscally restrictive Growth, Employment and Redistribution strategy (GEAR) had the effect of worsening poverty. In the realm of health it caused a freeze in levels of public spending that severely damaged health services through not replacing staff exiting the health service, and through moratoriums on recruitment. GEAR was successfully opposed by civil society, particularly by the trade unions, leading to its *de facto* abandonment in 2002.

³⁶ A recent book about assassinated Mozambican journalist Carlos Cardoso (P. Fauvet & M. Mosse, *Carlos Cardoso, Telling the Truth in Mozambique*, Double Storey, Cape Town, 2003) graphically describes the corrupting of Frelimo, largely by elements within the party. The absence of civil society, obliterated by years of civil war, left it to journalists like Cardoso to reveal what was taking place.

NGOs or political parties are often used as vehicles to advance a hidden agenda, and South Africa is no exception. However, a distinction must be made between organisations where there is evidence of this, and a paranoia that castigates all independent opposition as having a hidden agenda. It is also important to note that generally governments succumb to this pressure unless they feel enough of a counter-pressure from their own civil society or are brave and principled enough to denounce it. The counter-pressure mobilised by COSATU, with its campaign against GEAR, is an example of how anti-poor policies can be successfully contested from below with a proper mobilisation. So, too, is the TAC campaign against the Pharmaceutical Manufacturers Association (PMA) whose litigation was undoubtedly hatched in boardrooms in New York and London, but was defeated on the streets of Pretoria.

Campaigning for medicines that can save people's lives does not make an organisation an agent of the drug company that makes the medicines. Debates about public health are also distinguishable from debates about economic policy. To the extent that TAC reflected international pressure, it was to demand that the best practices and advice of multi-lateral institutions such as the World Health Organization and UNAIDS would be accepted and acted upon. It is important to note that in relation to HIV/AIDS policy, there has been no pressure by external international or other bodies to route AIDS policy down the path of denialism. In fact, the opposite has been the case. By opposing a national treatment policy, South Africa placed itself at odds with the rest of the progressive world, including middle-income countries such as Brazil, who were prepared to risk economic sanctions from the World Trade Organization and the United States in the interests of providing affordable generic medicines to people with AIDS. Ironically, the AIDS denialists, who are homophobic and on the political right, make strange bed-fellows for a party of the poor committed to advancing all rights and freedoms.

This reasoned approach has prevented TAC's opponents from gaining credence for their depiction of TAC as merely an anti-government tool, with a hidden agenda, being secretly funded as a battering ram against the ANC. Despite people like Ntshangase holding influential positions in the ANC, their claims have never gained currency in the middle leadership and the rank and file.

In the light of TAC's ability to counter untruthful propaganda, it has been argued that the decision to launch a 'Civil Disobedience Campaign' in 2003 was a mistake and that it made reconciliation between TAC and the ANC impossible. In its defence, TAC would point to the fact that civil disobedience was a last resort. It came about as a result of the failure to get the ANC to even consider a national treatment plan, despite

numerous meetings, memoranda, demonstrations, legal processes and negotiations at the National Economic Development and Labour Council (NEDLAC). In the face of an unwavering refusal to agree to ARV treatment, TAC leaders felt that the campaign for treatment would fail if it did not initiate a more radical form of protest.

The TAC leadership appreciated that the civil disobedience campaign would require crossing a threshold of conduct that was likely to alienate some of TAC's public support, and possibly irretrievably alienate government and the ANC. COSATU, for example, adopted a neutral position which recognised the 'frustration with the government's delay', but lamented that: 'the use of the term 'civil disobedience' is unfortunate and must be clarified. COSATU's view is that 'civil disobedience' means breaking unjust laws, mainly against illegitimate governments.' COSATU 'reaffirmed full support for TAC' even while distancing itself from the campaign (COSATU, 2003).

But the dilemmas felt by some of the TAC leaders were not shared by TAC's volunteers. As previously explained, TAC's day-to-day work actively builds and promotes leadership of people with HIV. This means that the voices, and when necessary the votes, of those most directly affected by the AIDS epidemic retain power in TAC, and that at critical points TAC does not succumb to middle-class sensibilities or political loyalties. These voices argued that TAC's constitutional mandate was to win the right to treatment for the 600 people dying of HIV-related illnesses every day, not to be a darling of academics or the press, or an ally of the ANC alliance.³⁷ For community-based activists, four years of AIDS denialism meant that the time had come for a confrontation to end the political prevarication about HIV/AIDS.

Significantly, the public response to civil disobedience was not predominantly hostile. Despite commencing a day after American President George Bush had launched his unlawful attack on Iraq, and the understandable preoccupation of the world with this war, the campaign was high on the news in South Africa and internationally. It sparked intense media debate, illustrating that while polite society welcomes a civil society movement that is skilful, loud and non-threatening, there is ambivalence when the poor do away with decorum, display unmediated anger and break the law. But the response was ambivalence rather than condemnation, and the issues that had sparked the campaign were not lost. Steven Friedman, for example, wrote that:

³⁷ The figure of 600 deaths a day was based on government statistics indicating that there were an estimated 200 000 AIDS related deaths a year by 2000. TAC's media campaign ingrained this figure in the national consciousness in early 2003.

Disobedience inspired by HIV/AIDS policy indicts our democracy, not the impatience of the protesters. Do the activists and the HIV and AIDS sufferers for whom they seek to speak indeed have a say in the policy on this issue – and therefore a democratic opportunity which they are spurning?³⁸

Although causing great enmity within the ANC leadership, the civil disobedience campaign did achieve its objective, and four months after it was suspended on the request of Deputy President Jacob Zuma, Cabinet announced a commitment to a new treatment plan which would include access to antiretroviral medicines for people with HIV/AIDS.

The end of denial?

The convergence between the ANC and TAC on the issue of treatment should have been the basis for re-building a civil society-government partnership because, in the words of ANC Secretary General Kgalema Motlanthe 'We are in the same boat with TAC now' (*City Press*, 28 February 2004).

That has not happened, however, and despite ongoing efforts by TAC to work with all levels of government the tensions remain. In July 2004, the Minister of Health derided TAC as a 'single-issue interest group', a claim obviously given Presidential sanction by virtue of the fact that it was carried in the President's weekly electronic newsletter (*ANC Today*, 7 July 2004). This is inaccurate. The campaign for access to treatment raised a multitude of issues linked to politics, economics and health – and has always demanded a political response. TAC has also been accused of overlooking poverty and demanding a bio-medical approach to HIV whose sole objective is to put antiretrovirals in people's mouths. There is ample evidence to show that this, too, is inaccurate. For example, as far back as 1998, the AIDS Law Project made a submission to the Poverty Hearings which pointed to the nexus between poverty, income disparity, gender inequality and risk of HIV. But it also warned that 'HIV infection leads directly to even greater poverty and inequality'.³⁹ Ironically, TAC's approach to the relationship between poverty and HIV corresponds closely with that of President Mbeki's. During campaigning for

³⁸ *Business Day*, 25th March 2003.

³⁹ AIDS Law Project, *How the Poor Die: HIV/AIDS and Poverty in South Africa*, Memorandum for the SA Human Rights Commission/Commission on Gender Equality, National NGO Coalition Hearings on Poverty, 22 May, 1998.

the April 2004 General Election, Mbeki told a rally in KwaZulu-Natal that: 'You can't really go to someone who is hungry on Monday and say 'here is a tractor, go and farm and you will only have food in four months.' When a person is hungry, he needs food immediately' (*Sunday Times*, 11 April 2004). The same applies to a person with advanced HIV infection (AIDS), who needs life-saving treatment immediately. A delay will cause that person's death. Therefore, what is needed is a commitment to saving lives in the short-term together with a plan to urgently address the socio-economic factors that underlie the HIV epidemic in the medium- and long-term.

In making these claims on government, TAC continues a tradition of human rights advocacy that the ANC itself pioneered. Its approach to HIV/AIDS recognises that in the 21st century poverty remains the greatest determinant of inequality and human rights violations. As health activists such as Dr Paul Farmer would attest, HIV/AIDS is but one manifestation of the many types of structural violence inflicted on the poor (Farmer, 1999). But the twenty-first century is unlike previous centuries when those with power and wealth could reap the benefits of exploiting the poor – or simply ignore their anguish – and suffer almost none of the consequences. The experience of South Africa illustrates that HIV/AIDS, environmental degradation, crime and other social evils, while predominantly affecting the poor, have consequences that spill into society as a whole. Erecting walls and fencing off nature reserves can give the rich only limited security. Ultimately, the social consequences of HIV will be borne by society as a whole.

A report on crime in South Africa released by the South African Police Services in 2003 confirms how HIV/AIDS is inextricably tied to the causes and consequences of poverty in South Africa. It notes that:

[HIV/AIDS] may already have become conducive to crime in that police officers and other officials serving the criminal justice system may also contract the disease and become demoralized and/or medically unfit to render a service. In addition [the orphaning of children] will of course affect the socialization of children and their future prospects' (SAPS, 2003).

These are the reasons why the Treatment Action Campaign has always demanded that those who control South Africa's power and resources, either privately or publicly, must ultimately choose to pay 'upfront' for HIV prevention and treatment or pay 'downstream' to try and mitigate the impact of an epidemic of orphans and social

dislocation. The price of AIDS denialism will be social dislocation, rising crime, falling living standards – consequences that will be difficult to conceal indefinitely.

The objective of the TAC has been to save lives. The change in policy announced by government in November 2003 and the commitment to providing treatment to people with AIDS was a major step forward. It should have been the basis for rebuilding a partnership against AIDS on the foundation of a government-led Plan that has been welcomed by everyone. The next step for TAC and the government should be re-prioritising the agenda to build the capacity and quality of the public health service and to realise the vision of the ANC's 1994 *National Plan for Health*. The medical response envisaged by the Plan requires that the health system be reinvigorated. Given the magnitude of the task, this too necessitates a new partnership with government, particularly as powerful private health sector interests will try to block or limit transformation.⁴⁰

Two questions therefore arise in conclusion. The first is whether the period of divisive AIDS denial is now over. The second is whether the TAC, government and all other social partners can put behind them a divisive and painful chapter in the history of South Africa's response to HIV and work in tandem to prevent new infections and improve the lives of as many as possible of the five million people already infected. Unfortunately, neither question can be answered definitively. It might thus be better to assert on behalf of the vision of the new South Africa that an answer in the affirmative to both questions is a moral, ethical and legal imperative.

References

African National Congress. 1994. A National Health Plan for South Africa. Pretoria. Available at www.anc.org.za/ancdocs/policy/health.htm

African National Congress. 2002. *Castro Hlongwane, Caravans, Cats, Geese, Foot and Mouth and Statistics – HIV/AIDS and the Struggle for the Humanisation of the African*. January 2. Available at www.virusmyth.net/aids/data/ancdoc.htm

African National Congress. 1993. *The Reconstruction and Development Programme, A Policy Framework*. Pretoria. Available at www.anc.org.za

Bradshaw, D., Laubscher, R., Dorrington, R., Bourne, D. & Timaeus, I. 2004. Unabated Rise in the Number of Adult Deaths in South Africa. In *South African Medical Journal*, Vol. 94, No. 4, April, pp 278-279

Cameron, E. 2003. Top Judge Slates Government's Dead Hand of Denialism. In *Mail & Guardian*, 17 April. Available at <http://ww2.aegis.org/news/dmg/2003/MG030410.html>

⁴⁰ After 1994, several major pieces of legislation that aimed to restructure and regulate the health system met with opposition from multi-national pharmaceutical companies or medical aid scheme administrators.

- Community Health Media Trust. 2002. *Patient Abuse, TAC's Struggle for Access to Treatment*
- Department of Health and Health Systems Trust. 2002. Report from the *National Scientific Consultative Forum on HIV/AIDS, Getting Scientific Knowledge into Policy, Turning Knowledge Gaps into Research*, August 13-14
- Department of Health. 2003. *National HIV and Syphilis Antenatal Seroprevalence Survey in South Africa*, 2003. Pretoria. Available at www.health.gov.za
- Fauvet, P. & Mosse, M. 2003. *Carlos Cardoso, Telling the Truth in Mozambique*. Cape Town: Double Storey
- Government Communication and Information Service. 2002. *Statement of Cabinet on HIV/AIDS*. April 17
- Government Communication and Information Service. 2003. *Towards a Ten Year Review*. Pretoria
- Govender, P. 2004. *Reasserting the Politics of Power as Love and Courage: Experiments in a Decade of Democracy*. Ruth First Memorial Lecture, 21 April, Johannesburg
- Hammer, S. M. 1996. Establishment of Combination Treatment as the Preferred Method to Treat HIV. In *New England Journal of Medicine*, 355 1081-90
- Hammer S. M. 1997. A Controlled Trial of Double versus Triple Therapy for HIV. In *England Journal of Medicine*, 337, 725-733
- Heywood, M. 2003. Preventing Mother To Child HIV Transmission in SA: Background, Strategies and Outcomes of the TAC Case Against the Minister of Health. In *South African Journal on Human Rights*, Vol. 19 (2)
- Kramer, L. 1997. *Reports from the Holocaust: The Story of an AIDS Activist*. New York: Cassell
- Mbali, M. 2002. *Mbeki's Denialism and the Ghosts of Apartheid and Colonialism for Post-apartheid policy making*. May. Available at www.nu.ac.za/ccs/files/mbeki.pdf
- Mbeki, T. 2001. Letter from T Mbeki to the Minister of Health. In *Business Day*, September 10, 2001
- Mbeki, T. 2001. Z. K. Matthews Memorial Lecture, Fort Hare University, October 12th
- Makgoba, M. W. 2002. Politics, the Media and Science in HIV/AIDS: The peril of pseudoscience. In *Vaccine* 20 1899-1904
- Makgoba, M.W. 2002. Interview in *Focus Light on Southern African Politics*, Helen Suzman Foundation, 18, June
- Mandela, N. 2000. Closing Address at the 13th International AIDS Conference, Durban, 14th July
- Mankahlana, P. 2000. *Building a Monument to Intolerance: Response to Enquiries and Comments on HIV/AIDS*. Press statement, Office of the President, Pretoria: 23 March
- Mankahlana, P. 2000. *Just Stick to What Mbeki Said*. Press statement, Office of the President, Pretoria. 23 March
- Members of the Faculty and Staff of Harvard University. 2000. *Consensus Statement on ARV Treatment for AIDS in Poor Countries*
- National AIDS Convention of South Africa (NACOSA). 1994. A National AIDS Plan for South Africa, 1994-1999
- Report of the Joint Monitoring Committee on the Improvement of the Quality of Life and Status of Women, 'How Best Can South Africa Address the Horrific Impact of HIV/AIDS on Women and Girls', November 2001

- Schoofs, M. 2000. Flirting with Pseudo-Science. In *Village Voice*, March 15-21
- South African Democratic Teachers' Union. 2000. Sorry, Mr President, We Cannot Infiltrate Ourselves. In *The Educators' Voice*, Vol. 4:8, October
- The Citizen*, 20 February 1998. 'Doctors welcome AIDS transmission trial results'
- The Mail & Guardian*, March 22 2002. 'AIDS drugs killed Parks, says ANC'
- The Star*, March 5, 2002. 'Mandela's AIDS drug call is an act of conscience'
- Treatment Action Campaign. Electronic Archives at www.tac.org.za
- UNAIDS/OHCHR. 2002. International Guidelines on HIV/AIDS and Human Rights. Revised Guideline 6. Geneva