

SOUTH AFRICA'S STRUGGLE: THE OMISSION AND COMMISSION OF TRUTH ABOUT AIDS

A nation, previously divided by race, now threatens to be destabilised by gender inequality, violence, and disease. A truly African solution would be to set up an HIV truth and reconciliation commission, where under strong health policy and scientific leadership, everyone could come together and reach a consensus on how best to draw a line under past misguided views and to move forward with convincing strategies. Only then can South Africa's leaders give hope to future generations.¹

‘TO APPEAR LIKE NORMAL ILLNESS’

In 1987, the President of Zambia, Kenneth Kaunda announced that his son, Gwebe, had died of AIDS.² ‘It does not need my son’s death to appeal to the international community to treat the question of AIDS as a world problem’, the senior Kaunda said.³ The epidemic that had begun in northern central Africa was rapidly making its way south. In that year, there were approximately 51 cases of AIDS known in South Africa.⁴ 18 years later, Nelson Mandela’s son, Makgatho Mandela, died on 6 January 2005. Two of Africa’s best known and greatest former presidents had lost their sons to AIDS. In the intervening years, HIV prevalence in South Africa had rocketed from near zero to as many as 5.5 million people who were estimated to be living with HIV at the end of 2004⁵, while perhaps 1.5 million had already died⁶ by the time Nelson Mandela lost his son.

Mandela, who had made efforts to ‘normalise’ the image of AIDS in South Africa, and who had campaigned for AIDS to be recognised and treated like any other disease, said at his son’s funeral,

Let us give publicity to HIV/Aids and not hide it, because [that is] the only way to make it appear like a normal illness.⁷

It was exceptionally important for Nelson Mandela to say this, but he should not have had to say it all. Half a decade into the new millennium, South Africa had by far the worst HIV epidemic in the world, and yet there was still debate about how to deal with it. The principal question was whether it could be considered ‘normal’ and, more than this, ‘normal’ in whose terms?

¹ Editorial in *The Lancet*, 20 May 2006

² The History of AIDS, 1987-1992, AVERT, online: http://www.avert.org/his87_92.htm; Bureau of Hygiene & Tropical Diseases (1987), 'AIDS Newsletter', Issue 16; Cameron 2005:79.

³ Cameron 2005:79.

⁴ UNAIDS/WHO Epidemiological FactSheet 2000.

⁵ The 2006 UNAIDS report estimated that the number of people living with HIV to be 5.5 million with an error range of 4.9m – 6.1 m.

⁶ Actuarial Society of South Africa, Summary Statistics. This model shows total accumulated deaths from AIDS at the middle of 2005 to be 1,477,556 for South Africa, based on earlier statistical trends. See <http://www.assa.org.za/aids/content.asp?id=1000000449>

⁷ BBC.co.uk (2005), 'Mandela's eldest son dies of Aids', 6th January 2005. <http://news.bbc.co.uk/1/hi/world/africa/4151159.stm>.

Of course, it was 'normal' if this is taken to mean common or average. Black South Africans are aware of the terrible toll that AIDS is taking because of the number of funerals they have to attend. When someone dies, almost everyone who knew the deceased is expected to attend the funeral. All family and relatives, friends, colleagues, fellow church members, work mates, and any one else who has had more than casual contact with the deceased and who hear about the funeral in time will try to attend. Nearly everyone appreciates the tremendous strain that this has put on resources. With the rise in deaths municipalities are running out of room in cemeteries, while families and households grieve, collapse, and sink further into poverty. In this, AIDS is now 'normal'. Mandela's words are more complex than this: he says that South Africans must do what they can to make AIDS *appear like* a normal illness. In fact, it still does not even appear as an illness to many South Africans who continue to deny its existence, especially in death. In announcing the death of a colleague at the national broadcaster, SABC, the news reader noted that one of their weather announcers had died of 'AIDS related illness' on June 15 2006. This was a departure from the way deaths from AIDS had been announced previously. People were said to die 'after an illness'. The indirect reference to an undefined illness, however, had already come to signify death from AIDS. In this way, it was as normal as the hidden network of sexual relations that drove it: everyone knew it was there, but no one would admit to the fact. AIDS was becoming normalised as a missing presence. It does not *appear*.

Mandela's successor, Thabo Mbeki, has fought mightily against accepting this reality. At the other end of the political spectrum, people in rural villages, and especially traditional healers, debate whether AIDS is curable, and some claim to cure it. The essence of the debate is whether the ancestors knew about AIDS. If they did, then traditional medicine ought to be able to cure it because it is an African disease among Africans; if they did not, then they can't and we must die. The struggle against AIDS, then, depends on a peculiar image of its nature and origins, an image that is deeply embedded in a South African cultural imagination. South Africans ask themselves, "Is AIDS 'ours', African—from 'us' and within us—or is it foreign, un-African, from without rather than from within?" This is not unusual in South Africa today. South Africans, for instance, typically blame the worst aspects of crime on people they call 'Africans', that is, immigrants from Africa north of the South African border. For South Africans, especially black South Africans, what they call 'Africa' is a dangerous and foreign place. The deep ambiguities of reference to what is 'ours', that is 'African' or 'South African', and what comes from outside and what comes from 'inside' create significant barriers to acceptance.

Uganda had already made this determination years before the virus was discovered, described by science and named. It had its own name for it, and recognised it as its own problem, for which Ugandans must come up with a solution. There were of course many who helped to find solutions, but Uganda's ownership of the problem facilitated its response. South Africa, especially its leadership, has not accepted this burden of possession, for the most part, and so still wanders through a nightmare of uncertainty.

This 'denialism', as it has come to be called in South Africa, has characterised the response to AIDS almost from the start.⁸

In the late 1980s, HIV was still scarcely noticeable in South Africa. There were a few discussions of it in the newspapers, but these all pointed fingers at Africa north of the South African border. It was implied that it would not affect South Africa. Indeed, in the dying days

⁸ 'The South African response to HIV epidemic has been characterised by a unique form of denialism in the highest echelons of political power' (Abdool Karim 2005:31).

of Apartheid, there were those who thought this might be a good thing as it would result in the deaths of black Africans. While this attitude was not expressed in the public press, so far as I am aware, it was expressed at dinner parties and garden gatherings. The South African Broadcasting Corporation, the state-owned and sole broadcaster in South Africa ran a few stories on the new disease that had been reported in Uganda, and that had been identified in migrant mine workers, especially from Malawi. The contracts for these workers were subsequently cancelled. Dr Willie van Niekerk, Minister of Health and Population Development (precursor to the current Department of Health) proclaimed in 1988 that “Promiscuity is the greatest danger, whether one likes it or not,” in reference to homosexuals and foreign black mine workers. Dr Marius Barnard, the shadow minister for health in the parliamentary opposition, the Progressive Federal Party, suggested that HIV/AIDS “carriers” should be isolated as they were in Cuba.

Most people had other things on their minds, however. South Africa was in the midst of rising violence in the townships as bomb blasts and protest actions gradually gathered in force and urgency. 1985 was a watershed year in which violent events by both police and resistance movements became, if not commonplace, at least alarming. In that year, South African churches, led by Bishop Desmond Tutu began to campaign steadily and forcefully for change. Armed police patrols began moving through South African townships, and several groups of protesters and innocent people were killed. In an attempt to reassert control over the rising violence, the Prime Minister, P W Botha, offered to release Mandela if he agreed to forswear violence. Mandela refused to do so and remained in prison. Instead Botha declared a state of emergency. It was to last for the remainder of the decade, until F W De Klerk succeeded a tired and confused Botha as Prime Minister in August 1989. The events of the last half of the 1980s made it clear to everyone that the end of Apartheid was merely a matter of time. It came sooner than most expected, and without major bloodshed. In February 1990, soon after taking office, De Klerk effectively declared the end of Apartheid by announcing that he was unbanning the political parties that had led the resistance to the Apartheid government, including the ANC and the South African Communist Party. He began to release political prisoners and acknowledged the end of the Apartheid regime. He announced, too, that Nelson Mandela would be released, and Mandela finally walked free on 11 February, 1990. Prime Minister De Klerk led his party to the negotiating table with the recently unbanned ANC, together with all of the other parties from the left and right. Fifteen years later, the remainder of the National Party, the old party of Apartheid, quietly folded itself into the triumphant ANC, which after two democratic elections commanded two-thirds of the vote.

By the end of 1991, the first formal negotiations aimed at founding a new government were begun, but ended in failure because of the continuing violence in South African townships. The negotiations were called the Convention for a Democratic South Africa. On 20 December of that year, Mandela spoke to the Constitutional Assembly, saying

Today will be indelibly imprinted in the history of our country. ... [T]oday will mark the commencement of the transition from Apartheid to democracy. ... History will judge us extremely harshly if we fail to turn the opportunity, which it now presents to us [to the] common good. The risks of further pain and affliction arising from violence, homelessness, unemployment, of gutter education, are immense. ... The price of CODESA's failure will be far too great.⁹

⁹ Address to CODESA by Comrade Nelson R. Mandela, President of the ANC, 20 December 1991. <http://www.anc.org.za/ancdocs/speeches/1991/sp911220.html>.

Eventually a series of negotiations was successful in writing a new constitution and the first full-franchise democratic elections were held in South Africa in April, 1994. On May 10th of that year, Nelson Mandela became the first president of what was soon to be called, informally but proudly, 'The New South Africa', or the 'new dispensation'. As Mandela's CODESA speech suggests, the burden of the past was far too great to give equal attention to the reform of government and all of its aspects, to the ending of violence that had by this time become pervasive and increasingly arbitrary and aimless, and to everything else that must be done. It was imperative that the moves towards a new government not fail. Everything else rested on this. The efforts were successful, of course, but the rising tide of HIV was lost from sight.

Efforts to control AIDS, however, were beginning by 1990 when the first survey of ante-natal clinics shows that 0.7–0.8% of pregnant women attending the clinics tested positive for the HI virus.¹⁰ The survey provoked little notice in the press, but the Department of Health has continued to conduct surveys annually since that time. It was not until 1992, however, that the first significant efforts were made by government to address the problem, but when it did, their efforts were heavily burdened with a political legacy and ideological agenda that did nothing but divide and fragment efforts from the beginning.¹¹ By now, much has been written on AIDS in South Africa.¹² This chapter offers, in particular, a synoptic view of cultural meanings and contrasting political discourses around AIDS that have affected the relationship between South African people and their government and civil society.

THE SHAPE OF THE SOUTH AFRICAN RESPONSE

HIV crept into South Africa just as political power was being smoothly transferred from the old party of Apartheid, the Afrikaans-dominated National Party (NP), to the predominantly-black African National Congress. The shape of the response to AIDS was already being formed even as South Africa was negotiating the transition. Although the impact of any serious efforts to combat AIDS would not be felt in South Africa until sometime toward the end of the decade, two pivotal events seem to have begun to direct it. The first of these was a firm foundation in a human rights approach that was entrenched by the formation of the National AIDS Committee of South Africa, the founding of the AIDS Law Project (ALP) and the organisation of the AIDS Consortium, all in 1992. These three organisations determined that the approach to AIDS in South Africa would have much in common with the approach that was taken in the USA, especially that which developed around gay organisations in California and New York. They also adopted the struggle tactics that had been developed during the decades of active political struggle against Apartheid. These organisations gave birth later to the 'Treatment Action Campaign' (TAC), an organisation built around demands for treatment rather than prevention. TAC used the media and strong confrontational political tactics in direct struggle with government, while ALP provided support for challenging the government in court. The second development was the founding of 'Soul City', an 'edutainment' organisation that proposed to use entertainment to educate the public about HIV and AIDS and other health and development issues. The Soul City programme was based in the 'Institute for Health and

¹⁰ Department of Health, South Africa 2000.

¹¹ Van der Vliet 2001; Van der Vliet 1994: 119; Van der Vliet 1996.

¹² The principle recent works on AIDS in South Africa include the following: Barnett & Whiteside 2002; Campbell 2003.; Chirambo, Caesar 2003; Dorrington, Bradshaw, Johnson & Budlender 2002; Dorrington, Bradshaw, Johnson & Budlender 2004; Heywood 2004; Abdool Karim & Abdool Karim 2005; Kauffman & Lindaur 2004; Natrass 2004; South African Department of Health 2006; Cameron 2005, and van der Vliet 2001, among others. In addition, a book of poetry and stories, 'Nobody ever said AIDS' (Rasebotsa, Samuelson & Thomas, ed. 2004) gives deep personal and literary insight into South African's experiences with living with HIV and dying of AIDS.

Development Communication'. This was followed by the establishment of LoveLife, an organisation that used mass advertising—billboards, glossy publications, and road shows as a means to educate people about HIV. This initiative helped to channel funds and government attention towards mass media as the principal means for communicating their message. From the start, South Africa's strategy has been highly political, centralised and based in expensive high-tech mass media. Echoing the rhetoric of the what is called in South Africa, the struggle against Apartheid, or just 'The Struggle', Nelson Mandela called the efforts to halt the epidemic 'The new struggle.'¹³ Prevention messages have been indirect, often obscurely so, and explicit sex education has been consistently resisted. Discussion of AIDS in the media routinely places it in a political context.

These approaches contrasted strongly with Uganda's approach which emphasised communication strategies based in small organisations, schools, businesses, churches, and community theatre with popular but indigenous music. It was highly decentralised, non-political (President Museveni had banned political parties and decentralised government), and it emphasised medical-technical approaches to both prevention and treatment. Prevention messages were sexually explicit with wide-spread use of direct and explicit sex education in schools with significant media support and educational materials. While the president of Uganda offered encouragement and direction, he generally delegated to technically competent individuals. He did not so much lead the way as get out of the way of implementation by others. The first president of the New South Africa, Nelson Mandela, paid little attention to AIDS during his presidency, while his successor, Thabo Mbeki, often obstructed effective prevention and treatment, preferring instead to direct an alternative course of action that appeared to have little scientific validity. His personal authority is pervasive in government and little happens without his direct or personal assent.

The two directions that the South African approach took—human rights and mass media—have had some contradictory results: one tending to entrench attitudes towards secrecy and privacy, the other encouraging openness and freedom of expression around HIV status. The focus on human rights has entrenched an attitude against personal 'disclosure' of HIV status and against mandatory testing in appropriate circumstances. Contact tracing has been discouraged, as have explicit messages and sex education.¹⁴ Research has often been hampered by bureaucratic insistence on complex 'ethical' research protocols based on those used in invasive medical procedures and drug testing. It has given legal force to many people's desire for privacy, but has also discouraged voluntary testing even with counselling. While this is not a bad thing in itself, it has tended to counter the other major direction in South African policy development, the effort to get people to 'talk about it'—one of the slogans used by the Soul City programmes and by LoveLife, South Africa's largest mass AIDS education NGO. The overwhelming move to public media, including prime-time entertainment, has emphasised the importance of 'speaking out' and 'talking about sex', especially for youth, and between youth and parents.

These two tendencies, though in some senses opposed to each other, have achieved an accommodation, and have come to define the South African response to AIDS. The emphasis on human rights enshrined in the new South African constitution and defended strongly by the courts has permitted effective challenges to the resistance from the Mbeki government.

¹³ van der Vliet 2001: 152.

¹⁴ Heald 2006.

AIDS and Human Rights

The convening in October 1992 of The National AIDS Convention of South Africa (NACOSA) was the first step in South Africa to address the problem.¹⁵ It received considerable funding from the European Union which had been funding AIDS programmes in South Africa since 1987.¹⁶ Its name, political constitution and results clearly reflected the success of the CODESA that had successfully met the huge challenges of political change. This was the year that HIV prevalence in Uganda began to plummet while, at the same time, it was just beginning its most aggressive rise in South Africa. Elements of the NACOSA plan were good: it was, at least, a start. It aimed to generate a unified national plan that that would direct a coordinated response. The conference was attended by 442 delegates, but the emphasis fell on what in retrospect seem to be very indirect concerns: racial inequalities, human rights and poverty. Instead of stressing an aggressive and integrated medical and epidemiological attack through research, prevention and palliative care, as Uganda had done, the conference pointed to the poverty of many South Africans and asserted that improvement in living standards was the key to prevention. Objectively, all but the poorest and most marginalised of South Africa's poor were not as poor as most Ugandans at the time, and had access to generally better health facilities. Even in the early nineties, South Africa was still loath to compare itself to any other African country. All South African parties to the political conflicts of the twentieth century sought comparison with the developed world, especially Europe and North America, and with the other English speaking Commonwealth countries of the south, that is, India, Australia and New Zealand. Comparison with other African countries where political violence, poverty, injustice and exclusion based on ethnic identity and race were often worse than in South Africa, was held to be 'odious' because it tended to weaken the moral force of resistance to Apartheid. This made political sense, but blinded most people to obvious comparisons with the rest of Africa. South Africans in general and the South African government in particular rarely looked to the north for ideas or solutions to problems. This was a tragic omission. Even though South Africans were in general much wealthier than most people to the north, it was in South Africa that HIV prevalence has reached its highest mark on the continent. To the north, countries were poorer, but their response to HIV was often superior.

The political-economic focus of the conference was consistent with the broader political environment of the transition to democracy, and seems to have taken this opportunity to address grievances rather than to address the problem. Race was also a significant issue, with black and white delegates believing that the 'other side' was responsible. Blacks believed that AIDS was still primarily a disease of white homosexual men or other Africans, and therefore not a problem for black South Africans. Some white South Africans saw AIDS as a problem with the pattern of black sexuality and family life arising from the disruptions of migrant labour and Apartheid laws that resulted in the break-up of black families who were not allowed by Apartheid laws to live together near their places of work. Even though HIV prevalence was already highest in Natal, a predominately Zulu province, the Inkatha Freedom Party that primarily represented a Zulu constituency did not attend the conference.¹⁷ This highly politicised and adversarial approach—as opposed to a dispassionate public health or technical one as exemplified by Uganda—continues to underlie much of the South African response. It was revitalised by the second president of the 'New South Africa', Thabo Mbeki, in his

¹⁵ Ijsselmuiden, Evian, Matjilla, Steinberg & Schneider 1993.

¹⁶ Baqwa 1996.

¹⁷ Ijsselmuiden, Evian, Matjilla, Steinberg & Schneider 1993.

campaign against exorbitant costs of ARV medications from the large pharmaceutical manufacturers.

It was already clear by this time, that Uganda's response to AIDS was exemplary even if it was not yet certain that HIV prevalence was falling. The NACOSA plan reflected strongly elements of South Africa's political transition by placing an emphasis on human rights and rights to confidentiality¹⁸ over more practical concerns. It attempted to assert national central control over provinces that had already begun to develop fairly effective local responses, especially in the Western Cape (where prevalence was still low) and in Natal (where prevalence had already increased to levels higher than Uganda at its peak). HIV prevalence was found to be as high as 13% among males who attended a STI clinic in Johannesburg, and 18.7% among females at the same clinic.¹⁹ A national AIDS coordinating committee was set up, and at a workshop in September 1993 attended by 40 people, drew up a document that encouraged 'grassroots' involvement in fighting AIDS, and required that the 'legacy of Apartheid' be recognised as a contributory factor to the spread of AIDS in South Africa.²⁰

NACOSA's invocation of 'grassroots' involvement—an important political strategy in the struggle against Apartheid, and a South Africa political buzzword that appears in virtually every speech even a decade and a half later—was meant to channel the political strength of 'the masses' against the new threat. But, unlike Uganda where significant political commitment and infrastructure was mobilised to do just that, the South African words remained just words. There was no political commitment to mobilise 'the masses' and the fabled 'grassroots' energy failed to materialise. At that moment, there was still too much work to be done to wind up the Apartheid regime, and later on many of the political activists had either received comfortable employment in government, or subsided into bitter unemployment.

An 'HIV and AIDS Charter' was drawn up in 1992 by several political activists including Edwin Cameron, Edward Swanson and Mahendra Chetty.²¹ The AIDS Charter²² was modelled on the Freedom Charter²³, written by Nelson Mandela and other ANC activists that had guided the ANC's struggle since its adoption in Kliptown, in June 1955. Since both Cameron and Mandela were lawyers, both Charters used the formal language of legal documents. The AIDS Charter used the Freedom Charter as its model in structure and wording. Cameron and others also set up, in 1992, the AIDS Consortium to coordinate NGOs and other organisations that were beginning to organise around the issue. Originally based at the Centre for Applied Legal Studies at the University of the Witwatersrand in Johannesburg, it moved out in 1998 to become independent, and in 2006 had over 1000 organisation affiliated with it. The AIDS Charter thus provides an orienting doctrine and legitimating charter for many of these organisations. The informal networked structure of the AIDS Consortium and its affiliates mirrored the structure of the organisation of the mass democratic movement during the 1980s in the last days of Apartheid. It is not, however, a legally binding document and has not been adopted by the South African state. The AIDS Charter clearly framed HIV and AIDS as political

¹⁸ Seidel 1996; Whiteside 1993.

¹⁹ Whiteside 1993.

²⁰ Whiteside 1993.

²¹ Cameron 2005; and AIDS Consortium website, <http://www.aidsconsortium.org.za/>

²² The AIDS Charter, in Zulu, English, Afrikaans, Sotho, Tsonga and Venda is available on the website of the AIDS Consortium, http://www.aidsconsortium.org.za/index.php?option=com_content&task=view&id=12&Itemid=41.

²³ African National Congress 1955, see <http://www.anc.org.za/ancdocs/history/charter.html>.

issues that, like Apartheid, required struggle to overcome. It also set the agenda for confrontational legal challenge as one of the bases for this contest. The fact that Cameron and the other drafters of the AIDS Charter were gay males, also gave them a sense of political disenfranchisement that was comparable to the disenfranchisement and oppression of the black members of the ANC. The struggle against AIDS then merged medical and political issues seamlessly, drawing on both American and South African experiences of racism and homophobia. Ironically, it simultaneously helped to suppress actual wide spread political mobilisation against AIDS. The politicisation of AIDS in South Africa seemed inimical to effective political mobilisation, perhaps because the era of mass mobilisation had passed—or was by now, most hoped, passé—or because the other pressing political issues simply overwhelmed it. In any case, what emerged as HIV tightened its grasp on South Africa was nothing like the Ugandan response.

The AIDS Charter closely parallels the Freedom Charter in many respects. The AIDS Charter, noting the threat of discrimination against people with HIV infections, ‘sets out those basic rights which all citizens enjoy or should enjoy and which should not be denied to persons affected by HIV or AIDS as well as certain duties’. Responding to the expulsion of HIV-positive foreign mine workers from South Africa by the previous government, the Charter declared that no restrictions should be placed on any person’s freedom of movement, just as the ANC’s Freedom Charter demanded ‘Freedom of movement shall be guaranteed to all who work on the land’. In response to suggestions that people with HIV should be isolated or quarantined, the Charter stated, ‘segregation, isolation or quarantine of persons in prisons, schools, hospitals or elsewhere merely on the grounds of AIDS or HIV is unacceptable.’ The Freedom Charter declared, ‘All people shall have the right to live where they choose.’ In line with the Freedom Charter’s demand for equal and free education for all regardless of race, the AIDS Charter mandated that ‘All persons have the right to proper education and full information about HIV and AIDS.’ In these and in many other respects—health care, security, education, employment, housing, gender, provision of justice, and so on—the AIDS Charter treated HIV positive people in political terms, and demanded their ‘freedom’. In short, the AIDS Charter aligned itself strongly with the ANC and the freedom movement in general by asserting an identity between people who had been discriminated against and disenfranchised for reasons of race with those whom they feared would be further discriminated against by reason of their HIV status or sexuality and sexual preferences. This was hardly an unreasonable fear since some infected individuals had already been killed and others thrown out of their homes or denied employment. The fears were valid, the mode of their expression familiar and commonplace, but their consequences were partly unforeseen.

The AIDS Charter, however, helped to entrench the politicised understanding of AIDS in the country. It prevented the possibility that AIDS might be seen as a disease like any other, as Mandela pleaded that it might on the death of his own son fifty years after the adoption of the Freedom Charter. While fully consistent with the human-rights based approach of most NGOs and left or liberal organisations. AIDS now had a political identity that other diseases did not have, and this effectively prevented mandatory tracing of sexual contacts that had become routine for syphilis, for instance.²⁴ As openly gay men, the authors of the AIDS Charter were fully aware that this was the approach taken by gay men in the US when AIDS was first discovered amongst them. They saw themselves as double victims of discrimination and stigma by virtue of their sexuality and their HIV status. In the midst of a struggle for the human rights of homosexuals in the US, this politicisation made sense; in Africa, faced with a generalised heterosexual epidemic whose proportions vastly exceeded that of the American gay

²⁴ De Cock, Mbori-Ngacha, & Marum 2002.

community, it was, perhaps, less appropriate. In any case, it made explicit a right not to divulge HIV 'status' to anyone, not even a current lover. This is embedded in the South African political consciousness.

Eventually, however, it appeared to be counterproductive. In 2002, De Cock et al identified what they called 'HIV exceptionalism' in the pages of *The Lancet*.²⁵ They argued that an approach modelled on Euro-American human rights issues and demands for privacy (unless the individual actively chooses to 'come out' and publicly declare their own HIV status) was not helpful in Africa where universal 'know your status' campaigns should be the norm and routine testing for HIV in all public facilities should become mandatory. The provision of social justice through treatment and accurate identification of HIV infections was more important than narrow legalistic interpretations of human rights, they said. The power of this argument grew, and Edwin Cameron, now a High Court judge, reversed his position on the right to non-disclosure of HIV status as a 'human right' in August of 2006, arguing—by this time with many others—that the provision for privacy and non-disclosure of HIV status prevented AIDS from being taken as a 'normal illness.' The crucial difference was that by 2006, unlike the situation in 1992, AIDS was now treatable and could be considered a chronic disease like diabetes. He recommended that routine tests be carried out for HIV wherever possible, and that reporting to responsible monitoring agencies be made mandatory. The South African government, however, has failed to take up even these suggestions.

AIDS NGOs and support organisations in South Africa explicitly adopted the style and often the substance of the underground anti-Apartheid movement of the 1980s. Surprisingly, the new government colluded in this by acting towards HIV positive people and those with AIDS in a way that was in many ways like the way the Apartheid state had acted with respect to black people. People Living with AIDS (PLWAs) and organisations that supported and represented them became political movements while the state manoeuvred to thwart them.

The tendency to central control by the national Ministry of Health was also already clearly present in the NACOSA plan. Indeed, two members of the eight-person drafting committee became ministers of health: Dlamini-Zuma and then Tshabalala-Msimang, and both resisted effective intervention to slow the progress of HIV.²⁶ At a time when Uganda was moving to decentralise control over AIDS control programmes, and thus to shift responsibility out to the local level and to the many parts of Ugandan civil society, government and economic institutions, the new South African government like the old continued to hold closely the secrets and mechanisms of state power. All in all, the contests around NACOSA effectively started South Africa on a course of adversarial politicisation with respect to AIDS. South Africa was still suffering from academic boycotts and cultural sanctions aimed at ending Apartheid. Though these had ceased by then to be useful, they continued to hinder the flow of new research on AIDS into South Africa. The 'go it alone' attitude that had come with 'sanctions busting' during Apartheid lingered on to isolate the developing South African response from the rest of the world. The political bickering continued to foster isolation even after May 1994 when the new government was finally installed.

The new government, however, immediately set about trying to implement the recommendations of NACOSA, and external agencies began to join in with increasing foreign aid. Still divided about the causes of AIDS, the bulk of the effort was placed on information, education and communication (ICT) strategies, and on reforming the government health care

²⁵ De Cock, Mbori-Ngacha & Marum 2002; Natrass 2004: 143, 146.

²⁶ Natrass 2004: 43; van der Vliet 2001: 160.

system so that it would permit access to the rural poor and to black people more effectively than it had done in the past.

Nkosazana Zuma, a former ANC activist was made the first Minister of Health under Nelson Mandela. She was the person ultimately responsible for the government's AIDS programme implementation. Nkosasana Dlamini, as she was then, before her marriage to Jacob Zuma, had qualified as a medical doctor in 1978 at the University of Bristol, UK, after going into exile in Britain as the result of her political activities in South Africa with the then-banned ANC. She was active in ANC politics in Britain while working as a doctor in two British hospitals before returning to southern Africa. She was Medical Officer in the Paediatrics Department of the government hospital in Swaziland from 1980 to 1985, where she met and married Jacob Zuma who later became Deputy President. She subsequently divorced him. She then left southern Africa again and became involved in exile in ANC politics overseas. On her return to South Africa in 1991 with many other exiles, she secured a post as a research scientist with the Medical Research Council in Durban. She had been a member of the steering committee of the national AIDS coordinating committee, and was chairman of the ANC Women's League in southern Natal region, among other activities. Her biography is typical of many of the current ANC elite who are often connected not only by their political relations and experiences in exile and the resistance to Apartheid, but also by a dense set of marriage and sexual links between its members, especially among the elite.

Nkosazana Zuma was well qualified for the new post, well connected with the ANC elites, and with practical experience as a medical doctor. It has therefore been a source of great puzzlement why she and her successor as Minister of Health, Dr. Manto Tshababla Msimang, should have been so contrary and reactionary in leading government AIDS interventions and programmes. As Minister of Health, Nkosasana Zuma was a central player in efforts to get the large international pharmaceutical companies to reduce the price of drugs used to treat AIDS and other tropical diseases, especially TB. Ironically, she then refused to allow government hospitals to dispense AZT, and prevented the use of Nevirapine in government hospitals for prevention of mother-to-child transmission of HIV until she was forced to do so by a court order.

Her major legacy in public health legislation was the passage of the Tobacco Products Control Bill in 1999 that effectively prevented smoking in all public places. Effective government-driven AIDS programmes languished while smokers were cleared out of pubs, government buildings and other establishments.

Under Nkosasana Zuma's leadership, the South African Department of Health also pursued a number of other strange directions. Several of these were extraordinary scandals as they did little to advance the cause of AIDS prevention, and a great deal of harm to the credibility of the South African government's ability to manage an AIDS prevention programme.

The 'Sarafina II' scandal

One of Nkosasana Zuma's first efforts was to commission an extraordinarily expensive musical entertainment. Mbongeni Ngema, a well known producer of South African musicals was hand picked to produce it. Ngema's previous hit musical, 'Sarafina', featured high energy Zulu song and dance with a weak story line about political struggle. It had been a great success in New York and London around the time of Nelson Mandela's release from prison. With the eyes of the world focused on South Africa, this play had highlighted South African cultural achievements—a film version was the first South African production to be screened at the Cannes Film Festival—and had presented the struggle against Apartheid in a highly positive light. It was perhaps not surprising that the Minister of Health would have thought that this

medium might be appropriate to promote a new HIV and AIDS prevention programme. Intentional or not, the idea for basing an AIDS prevention message in an anti-Apartheid film effectively fused the South African politics of struggle with the public health problem of AIDS. This might have been effective had it not run so rapidly off the rails during the financial free-for-all that developed around the newly powerful ANC elite as they took over the state and its resources.

In 1994, the European Union had granted the South African Department of Health 11 million ECUs for AIDS prevention programmes.²⁷ During June 1995 the Department of Health decided that a play or musical that presented the message in the form of popular entertainment would be a useful way to proceed. According to the subsequent report of the Office of the Public Protector, they then approached Ngema who gave an initial estimate of R800,000 for the development of an AIDS prevention play. The Health Department then formulated a plan to develop a touring play that would be 'culturally sensitive' and that would tour all of South Africa for 12 months. The terms of the tender were given as follows:

To supply a detailed script/framework and costing of the production.

The theatre production must consist of a play and music around the theme of HIV/AIDS awareness and prevention in South Africa. The play must be culturally sensitive to all people in South Africa. The company must have the capacity and infrastructure to tour the production country-wide for 12 months. The most important aspect of this play is the complete quality in all respects of the production. It must therefore be stressed that the highest quality must be obtained in the production and not the least cost.

The opening of the play must take place on the first of December 1995.

Consultation with the National HIV/AIDS and STD Programmes is essential.

The company must be committed not only to the prevention of HIV/AIDS and STD in South Africa, but the overall development of all its people.²⁸

Ignoring the usual tender procedures, the government AIDS Directorate invited tenders from only three entertainment companies and two companies presented tenders. One of them was Mbongeni Ngema's 'Committed Artists Theatre Company'. The short time-scale, political qualifications and other specifics clearly favoured Ngema who already had *Sarafina I* in production. Ngema's tender of R14 million for the production of *Sarafina II* was accepted over the tender of R600,000 from the other company. Predictably, *Sarafina II*, was a slightly remodelled version of the earlier international hit musical, with the same cast and story. It was first performed on World AIDS Day, 1 December 1995. The opening was attended by the European Community Ambassador, Mr Fouère.

Clearly, this involved misuse of European Community funds, and an investigation was immediately launched. The affair soon escalated to the level of international scandal. The play itself was never seen again, and the contract was withdrawn. The Office of the Public Protector was requested by the principal opposition party, the Democratic Party, to investigate, and the report of the Public Protector, Mr Selby Baqwa, was submitted to Parliament in May 1996. Baqwa's principle finding was simply that normal tender procedures had been ignored. Later that year, it was reported that an anonymous donor had come forward with R10.5 million to pay for *Sarafina II* so that the European Union funds could be returned. Since the 'anonymous donor' did not wish to be identified, there were fears that this involved some measure of

²⁷ The Ecu, or European Currency Units, was the predecessor to the Euro.

²⁸ Baqwa 1996.

influence buying or other corruption, or that there was no such 'anonymous donor' and the funds were actually coming from ANC party sources or from elsewhere in the government budget. The Minister of Health declared that because they could no longer ensure the anonymity of the donor, the offer had been retracted.²⁹ In any case, nothing more was heard of the recycled play whose message about AIDS was weak in any case. It was not until 1998 that a Special Investigative Unit pursued criminal charges against Mbongeni Ngema and managed to recover some of the government funds that had been spent on his non-play, most of which had been used to buy automobiles and to build an expensive house in Durban. By April 1999, Ngema had declared bankruptcy.

The rationale behind this effort remained obscure. In her report to Parliament, the Minister insisted that 'Theatre, as an art form, is no doubt a very powerful instrument for spreading health messages'. She accepted the charge 'that there were problems with administrative procedures and financial controls' but concluded that 'the play was a good idea'.³⁰ Noting that HIV prevalence among pregnant women in KwaZulu-Natal was already 18.2% and in Mpumalanga at 16.2%, the Minister declared her wish to 'recommit my Department to the struggle against HIV/AIDS which is a deadly scourge in our society.' She suggested that the criticism of the play by the public was because the play was 'about condoms'. She countered that 'it is not my intention to promote sex and promiscuity among teenagers' by advocating condoms, but insisted that:

... it should also be recorded that the message must also be very clear and simple. The major lesson from the play is indeed: "If you cannot abstain use a condom". Considering that 392 out of a 1000 children are born of children and the use of condoms does prevent unwanted pregnancies, sexually transmitted disease (STDs) and HIV/AIDS. I submit to you that even if that was the only message that the youth could learn, then that is possibly enough.³¹

Clearly, if the words of the Minister of Health can be taken to represent the views of the government of South Africa at the time, there was a large gap between the understanding of the enormity of the threat and the quality of the response. The language for their justification, 'if you cannot abstain, use a condom' had been borrowed from the Ugandan 'ABC' programme. Community theatre, plays and music had also been an exceptionally important tool in Uganda's AIDS programmes, but this was a far cry from what Uganda had done. An expensive commercially successful play that had been a musical hit in New York was an unlikely vehicle to carry the AIDS message to all South Africans, most of whom did not speak English, nor live in areas where the expensive lights and sound equipment could even be plugged in. The Minister diluted the concern with AIDS in her justification of the expenditure by mentioning the high rate of teen pregnancy and the prevalence of other sexually transmitted diseases. In short, the South African government at that time had no clear policy direction, and was not certain how to implement the limited policy that it had. As with other issues at the time, the politics of race and the politics of political transformation (and its attendant corruption) were put in the foreground.

²⁹ The public was never informed of who or what had been involved in this subterfuge. Eventually, it appears a consortium of 'South Africans from the private sector' came up with the funds to support the Minister and 'pledge[d] to support and pay for the play and support future endeavours that deal with AIDS' (South African Communication Service 1996).

³⁰ South African Communication Service 1996.

³¹ South African Communication Service 1996.

By contract, the use of music, dance and theatre to transmit messages about AIDS was highly effective in Uganda, but this was because Uganda's efforts were entirely home-grown, low-tech, and easily accessible. Plays were written by school children and teachers, not professionals. Music was local, often based in local idioms and languages. Theatre was scripted and performed by members of local communities in their communities. This was not the case in South Africa.

The scandal over Sarafina II and its high-tech and financial excesses were soon eclipsed by events around 'fast tracking' the so-called 'miracle cure' for AIDS known as 'virodene'.

The virodene scandal

Minister Zuma formally accepted claims by a company called 'Cryopreservation Technologies cc' (CPT) in Stellenbosch that they had a cure for AIDS. They called it 'Virodene'. She and Thabo Mbeki, then Deputy President, began to promote Virodene as a 'miracle cure for AIDS' partly on the basis that this was a South African 'invention' and represented an African solution to an African problem. They agreed to try to accelerate its acceptance by the Medical Control Council (MCC), the statutory body charged with certifying the safety and efficacy of all new drugs, and awarded it developer R3.7 million for further research.³² When the MCC refused to approve clinical trials on the reasonable grounds that there was no evidence of its effectiveness, but considerable evidence of toxicity, they accused the Medical Control Council with unjustified interference in their scheme to promote the 'drug'. This cure turned out to be little more than a highly toxic industrial solvent, dimethylformamide. In tones that indicated Mbeki's sense of betrayal by the MCC, he wrote about the matter in the ANC newsletter of March 1998.

More than twelve months ago, emanating from a request the Minister of Health [Nkosazana Zuma] presented through me [Thabo Mbeki], the Cabinet listened to a presentation by the Virodene researchers. Cabinet also had the privilege to hear the moving testimonies of AIDS sufferers who had been treated with Virodene, with seemingly very encouraging results. The Cabinet took the decision that it would support the Virodene research, up to the completion of the MCC processes. So far, this has not necessitated any financial or other material support. The Cabinet has not changed its mind on this issue. Those in Government, who deal with this matter directly, including the Minister of Health and myself, will continue to do so until Government policy changes. The importance of this is further emphasised by the fact that our entire system of government, from the national to the local level, has begun implementing a programme of action of sustained national mobilisation to intensify the offensive against the spread of HIV/AIDS ...

Mbeki and Zuma then cited some 'scientists' who were willing to support their claims, and concluded his message to the ANC party newsletter,

Alas, "the local review board", the MCC [Medicine Control Council], still refuses to accept the application, despite its knowledge of the unanimous opinion of these "learned and highly qualified professionals", and whose credentials it is perfectly aware of.

To confirm its determined stance against Virodene, and contrary to previous practice, the MCC has, with powers to decide who shall live or die, also denied dying AIDS sufferers the possibility of "mercy treatment" to which they are morally entitled.

³² Deane 2005.

I and many others will not rest until the efficacy or otherwise of Virodene is established scientifically. If nothing else, all those infected by HIV/AIDS need to know as a matter of urgency.³³ [All quoted phrases appear as in the original]

The details of any experiments or drug trials that might have taken place in the ‘research’ on Virodene’ were never released. Zuma and Mbeki, as Minister of Health and Deputy President, reacted to what they perceived as the ‘arrogance’ of the Medical Control Council. They had presented Virodene as an ‘indigenous’ discovery that promised, if not a cure for AIDS, then a ‘mercy treatment’ to which those who were dying were ‘morally entitled’. Their willingness to believe that such miracles were possible, entirely outside of normal scientific practice, indicates the depth of their denial that AIDS was in fact the most serious epidemic facing South Africa. While it was true that TB and malaria killed more people than AIDS at the time virodene was being discussed, by 2004 AIDS had indeed become the leading cause of death in South Africa.³⁴ Their sense of *moral* outrage, too, strongly suggests that they continued to see HIV as a moral problem rather than a ‘normal illness’. Some years later, Thabo Mbeki spelled out the grounds for his moral outrage in a document entitled ‘Castro Hlongwane, caravans, cats, geese, foot & mouth and statistics, HIV/AIDS and the Struggle for the Humanisation of the African’.³⁵ This document spells out most of the rationale for President Mbeki’s apparent rejection of the science of HIV and AIDS, and the views expressed are probably still those held by the President in 2006.

In 1999, when Thabo Mbeki was elected president and Nelson Mandela stepped down, Nkosazana Zuma was ‘re-deployed’ (in the terminology of the ANC ruling party that prides itself on its high degree of command and control from the centre) as Minister of Foreign Affairs.³⁶ In her place he appointed Manto Tshabala-Msimang who has carried on the ‘tradition’ of ‘denialism’ begun by Mbeki and Health Minister Zuma from the beginning of the epidemic.

While these dramas played themselves out at the top of the political hierarchy, considerable and extraordinary development of health care, including AIDS prevention, provision of antiretrovirals (ARVs) and highly active retrovirus treatment (HAART) regimes had already begun in private hospitals, and was carried out secretly in some public hospitals on a limited basis. This served as a kind of counterbalance to the misdirected leadership from the ministry of health and president’s office. The process of ‘grassroots’ development and civil society action in opposition to government, well established in Apartheid South Africa, now began to grow in response to government attitudes to HIV and AIDS.

HEALTH LEGISLATION AND POLICY

In the period since 1994, the South African Parliament has passed 29 separate pieces of legislation relating to health care providers and public health. These have covered important aspects not only of bio-medical practice and nursing, pharmaceutical provision and dispensing,

³³ Mbeki 1998.

³⁴ Doherty & Colvin 2004.

³⁵ The document was circulated amongst ANC party members and through email. It has been posted on the Internet (<http://www.virusmyth.net/aids/data/ancdoc.htm>) together with other documents pertaining to AIDS ‘denialism’, including those of Rasnick and others (African National Congress 2002). In the ‘properties’ of the Microsoft Word document downloaded from the ANC website, the ‘author’ field gives the name ‘Thabo Mbeki’, and reports that it was ‘created’ in April 2002. It is approximately 40,000 words in length. Under the title, the document is dated ‘March 2002.’ The document was accessed on the Internet in September 2006. There has been no effort to deny it or withdraw it by the South African government.

³⁶ Mbeki 1998.

but also alternative medical practices such as traditional healers, chiropractic, and homeopathy. These have transformed South African health care in profound ways by making many medications cheaper and improving service delivery to the poor, and in rural areas. None of this legislation, however, has directly addressed HIV and AIDS.

The ANC government inherited a health care system that was highly fragmented and which placed its emphasis on curative care, high-tech urban hospitals and the private sector.³⁷ Great strides have indeed been made to broaden the reach of public health initiatives and to make provision for primary health care clinics, and better serviced hospitals outside of the urban areas and for the poor.

Minister of Health, Manto Tshabalala Msimang approved the new five-year plan in 2000 that was meant to guide the government's response through 2005. The process began when she came to office in 1999 with a meeting that was meant to draw on as many sectors of the population and 'stake holders' (as anyone who may be an 'interested and affected party' is called in South African popular discourse) as possible. This included,

... faith-based organisations, people living with HIV infection and AIDS, human rights organisations, academic institutions, the civil military alliance, the Salvation Army, the media, organised labour, organised sports, organised business, insurance companies, women's organisations, youth organisations, international donor organisations, health professionals and health consulting organisations, political parties, and relevant government departments.³⁸

In addition, the resulting plan also noted that the minister consulted traditional healers in 'bilateral meetings'. The impression was given that there had been a broad poll of public opinion and stake-holder interests. Conspicuous by their absence was the AIDS Consortium and the Treatment Action Campaign, both offshoots of the AIDS Law Project, and other civil society organisation that had begun to oppose government. While sporting bodies and the Salvation Army were given a hearing, the most active civil society organisation concerned with AIDS, and most of South Africa's leading AIDS scientists were left out of the loop.

The situation by then was already reaching extreme proportions in some places. In KwaZulu-Natal Province in 1997, a prevalence of 63% was reported in one paediatric ward in a tertiary hospital,³⁹ while an adult medical ward in the same province tested 54% HIV positive⁴⁰ and a gynaecology ward in a district hospital yielded a figure of 42%.⁴¹ In Gauteng Province, the paediatric ward in a tertiary-level hospital one study found 29% already infected in 1996,⁴² while those in another paediatric ward were 18% HIV-positive by 1998.⁴³ While overall HIV prevalence was found to be 22.4% and 32.5% in antenatal clinics in KwaZulu-Natal according to the planning document,⁴⁴ many hospital wards already had a large burden of HIV-infected patients. The 'HIV/AIDS/STD Strategic Plan for South Africa, 2000-2005', committed the

³⁷ Forman, Pillay & Sait 2004.

³⁸ South African Government 2000.

³⁹ Pillay, Colvin, Williams & Coovadia 2001. 160 patients were tested. Cited in Doherty & Colvin 2004: 207 (table 17).

⁴⁰ Colvin, Dawood, Kleinschmidt et al. 2001; 507 patients were tested.

⁴¹ Wilkinson & Connolly 1999; 196 patients were tested.

⁴² Meyers, Pettifor, Gray et al. 2000; 507 patients were tested.

⁴³ Johnson, Henderson, Crewe-Brown et al. 2000; 176 patients were tested.

⁴⁴ South African Government 2000: 7.

government to following global guidelines for HIV and AIDS care, prevention, testing and monitoring as provided by the UN General Assembly special session (UNGASS) the WHO, and UNAIDS. HIV monitoring at antenatal sentinel sites was augmented with strict data collection protocols that ensured accurate data collection. Voluntary Counselling and Testing (VCT) centres were set up at most major hospitals.

Review of the achievements since NACOSA, however, was disappointing. Lack of trained personnel, inadequate funding, and failure to develop previously envisioned bureaucratic structures, lack of provincial level policies and people to drive them, absence of management protocols for prevention, care and testing, among many other failures were highlighted by the plan. To remedy this, the Plan appointed the Deputy President, Jacob Zuma, to drive new initiatives within government, and to strengthen an 'inter-sectoral and interdepartmental response with specific targets. There were also some shortcomings. As Leclerc-Madlala points out, however, this 'appears to mean little more than improved co-ordination and collaboration between various government ministries.'⁴⁵ The Plan took almost no notice of civil society, or of organisations outside of the government and the ANC party structures.

The Plan noted, however, that the 'The immediate determinants of the epidemic include behavioural factors such as unprotected sexual intercourse and multiple sexual partners,' while the 'underlying causes include socio-economic factors such as poverty, migrant labour, commercial sex workers, the low status of women, illiteracy, the lack of formal education, stigma and discrimination.' On paper, then, South Africa's plan for dealing with HIV and AIDS showed promise.

Just as the plan was being adopted, President Thabo Mbeki began to voice severe doubts about the direction the government was apparently taking.

⁴⁵ Leclerc-Madlala 2005: 846.