Dialogue

AIDS Denial in South Africa

Edwin Cameron

On May 17, 2002, *Green Bag* Contributing Editor Dan Currell visited Justice Edwin Cameron of the Supreme Court of Appeal of South Africa in his chambers in Bloemfontein. Justice Cameron served as a Judge of the High Court of South Africa from 1994 to 2000, briefly served as an Acting Judge of the Constitutional Court from 1999 to 2000, and became a Justice of Appeal in December, 2000.

– *The Editors*

The world is generally aware of the AIDS *epidemic in southern Africa, encompassing perhaps five million people in South Africa and as many as thirty to forty percent of the populations of nearby Botswana and Mozambique. But those outside southern Africa are less familiar with the history of the disease here, and the South African government's unusual response to it. Perhaps you can provide some background?*

AIDS started in South Africa at almost the same time as the first AIDS cases were diagnosed in America, in the middle of 1982. And the initial social profile of the disease was identical to that in the U.S. – white, affluent, mobile gay men. But within a few years that changed dramatically. By the mid-1980s it was clear from reports in central Africa that AIDS was running wildfire amongst the heterosexual population of the region. And we were on alert in South Africa that the epidemic looked likely to come our way with the same demographics – in other words, the heterosexual, black pattern of AIDS rather than the white, gay pattern.

I encountered AIDS in practice as a trade union lawyer in the 1980s, doing work with unions including the National Union of Mine

Workers and the Congress of South African Trade Unions – COSATU. AIDS had reached Malawi – a central African country bounded by Tanzania and Zambia – some years before the first heterosexual AIDS cases were discovered in South Africa. And there was a large contingent of Malawian mine workers who were suddenly tested without their consent, and they were transported back to their country when a fairly high HIV prevalence was discovered. So the union got involved, and thus I got involved in the issue.

To get personal – and I always do when discussing AIDS – as it happened, quite coincidentally, I was a young practitioner who had decided to pronounce my sexual orientation very assertively. At about this time I became infected with HIV – in approximately Easter 1985. I was diagnosed with HIV in December 1986. So my own involvement was double – as someone advising unions, involved in the social issue of the repatriation of the Malawian mine workers; and of course personally as someone diagnosed with HIV. But it was ironic to me that I didn't become involved in AIDS as a social issue as a gay white man or as someone living with HIV myself, but through my public interest practice with the unions in particular.

The Malawian mine workers episode of the mid-1980s taught a number of lessons. It proved that the conventional wisdom was correct: repatriations, isolations, screenings-off, quarantines don't work with HIV, for various reasons relating mainly to the mass nature of the epidemic. All of the Malawian mine workers were repatriated, but of course by that point the epidemic had already taken root. And by the early 1990s we had reached a critical point in South Africa for the development of the epidemic. By the mid-1990s we had a raging epidemic throughout the heterosexual population, and by the end of the 1990s nearly one in ten South Africans were infected with HIV. Four to five million South Africans in a population of just over 40 million.

You have just provided a "conventional" account of the AIDS epidemic in South Africa – but some members of the South African government would reject this account. Indeed, some in the African National Congress ("ANC") would go as far as to deny that AIDS as we know it even exists. What is the AIDS denial position?

My answer to your previous question really contains the seeds of explaining the denialist position: why do you have an epidemic that in Western Europe, North America, Australia and the rest of the world has been largely confined to what used to be called "risk groups" – gay men, intravenous drug users, hæmophiliacs, various other people – but in Africa you've got a mass heterosexual epidemic?

The AIDS dissidents originated in a tiny group of fringe scientists and historians mostly from the west coast of America; they initially explained the HIV epidemic in America as being an epidemic of gay lifestyle. They said it's not viral, and it's not infectious. The fundamental tenet amongst some of them is that HIV does not exist at all, that it has never been isolated. And 20 years after the first HIV diagnosis some of them are still – incredibly – propounding this view that HIV has not been isolated as a viral entity.

Of course, it has been isolated. There are thousands of top-level scientists throughout the world who have isolated it, who have written on it. But when dissidence becomes ideological, as with holocaust denial, reason doesn't function.

So the first tenet is that HIV has never been isolated. The second is that if it has been isolated, it is a non-harmful particle. They ascribe the mass deaths amongst homosexuals in the mid-1980s – and by the end of the 1980s I think the figure had reached three quarters of a million in the States – to "lifestyle". This in

truth was a covert form of blame. These were men who through inhalation of drugs and through injection of drugs and through sniffing of drugs and through partying and high living had really brought upon themselves the collapse of their immune systems. It wasn't simply an infectious agent which they had been unlucky enough to get. So the denialist position was an oblique form of homophobia.

But when the African epidemic arrived, the denialists were momentarily stumped. How do you explain that in an African population exactly the same symptoms are coincident with the introduction of a determinable infectious agent, namely HIV? So for Africa the dissidents were forced to come up with an entirely new explanation. Precisely what attracted the envy of a lot of homophobes in the United States, namely the relative affluence of some gay men, was the opposite amongst people in Africa – they lived in extreme poverty. So the dissidents did a double somersault and said, well, in Africa it is also a form of lifestyle – but the *opposite* form of lifestyle. It's not partying and high living and mobility, it's extreme poverty that causes the same symptoms.

The dissident position may have started in the United States, but recently some very powerful players in the South African government have taken a liking to it. How did this happen?

The explanation lies I believe in the stigma that still besets the epidemic. AIDS has from the start been associated with high levels of stigma and blame. It is fraught with guilt, fraught with condemnation. And if you try to trace the passage of a viral agent through a population or subpopulation, blame becomes rampant. Certainly as a gay man I can say that in the gay population high levels of HIV prevalence resulted from sexual transmission.

Now when you come to the central and southern African heterosexual populations, you've got to ask: is the virus travelling in the same way? Is it also sexual, as in the gay community? If it is – and I am not saying it is, since I'm not an epidemiologist – you then have to consider the thought, which the gay community had to consider, that serial successive sexual partners contributes to transmission. We faced that in the gay community. The steps we took, the publicity campaigns that we launched, the self-examination at an individual and community level were extremely difficult, but we did it. They're fraying at the edges now, and gay transmission is again expanding in the urban environments in Western Europe and North America, but we faced the issue.

Now, what of Africa? If you think HIV is sexually transmitted, which is what most epidemiologists and demographers say, are you going to blame people for having sex? And are you going to say that Africans have sex in certain specified ways which may or may not be comparable to the homosexual population? This is the fraught question, fraught because of the racial context, and fraught because of the value-laden position that the dissidents propound. And I believe that that is at the source – race and sex – of the dissident position in Africa and its endorsement by powerful people in South Africa.

Basically, the conventional account of AIDS leads one to conclude that there is a difference between African and European heterosexual practices – and that's politically loaded?

That's the distinction that the dissidents try to draw. And more importantly they are making a value-laden inference, that if you explain HIV transmission sexually you are condemning Africans' sexual behaviour: whereas I believe that the whole struggle of AIDS over the last two decades has been to de-value the disease, to de-normativise it, to say that this is just an infectious agent, so let's look at how it is transmitted and treated, let's combat the ways in which it is transmitted, let's do so without

condemnation or shame or guilt, but with full knowledge and appreciation of risk and of social context. And of course the dissident debate has re-normativised, re-shamed, re-stigmatised the whole discussion around the epidemiology of HIV.

One of the implications of the South African government's support of the dissident position has been, until recently, its refusal to publicly support or administer anti-retroviral drugs, drugs that appear to be very effective in treating AIDS. How does this fit into the AIDS denial picture overall?

Skepticism about the efficacy of anti-retrovirals goes back to the dissident position in the United States in the 1980s, and is part of the lunacy of that position. When people presented themselves with AIDS who had palpably not been partying late in New York's night clubs, but were schoolchildren or hæmophiliacs or gay men who had had only one or two unsafe sexual encounters in their lives and got infected with HIV, there had to be another explanation. The dissidents said well, of course, it's the drugs that are killing you – you're all on AZT, and that's why you're getting sick and dying. And as an ordinary matter of clinical fact, AZT is a toxic drug. This is not contentious – it's not even a particularly interesting fact because most drugs are toxic in some way or another. So the dissidents blamed the deaths of people from AIDS in the United States – when they weren't near-suicidal "lifestyle" deaths – as being due to the administration of AZT

And they've persisted in that position. The position has been adopted in its most sinister form amongst the African dissidents who link it to a corporate conspiracy to poison Africans. This is the most terrifying portion of the dissident doctrine: that there are western companies – North American and European companies – whose market for drugs is failing, who wish to create a market for the drugs in Africa, who wish to peddle toxic agents to Africans. And of course they wish to do so with a double agenda: first to maximise Western European corporate profits, and second, conveniently subsumed within the first, is to poison a large number of Africans because they are black. Like holocaust denialism, AIDS denial has a fundamental racial impulse: a racial suspicion, a racial anger, a racial fear, and a racial conspiracy.

The holocaust, of course, didn't happen – all the mountains of evidence testifying to the destruction of European Jewry in various ways – including, specifically, through gas chambers at Auschwitz: it's all manufactured, and it's manufactured of course because the Jews control the gold price and the world and the international organisations, and so on. It's at that level of racial conspiratorialism that AIDS denial in Africa also operates.

AIDS denial seems to have "legs" – the ANC has appeared to endorse it, and from some perspectives it looks like the dissidents are getting traction in South Africa.

President Mbeki convened a panel on AIDS which included some of these persons who are regarded almost universally as being on the irresponsible fringe of rational debate. The panel was convened on a public occasion two years ago, and the President himself has expressed views which are consonant with the dissident position on AIDS. A document was circulated by the ANC in April 2002 called *Castro Hlongwane, Caravans, Cats, Geese, Foot & Mouth and Statistics: HIV/AIDS and the Struggle for the Humanisation of the African*. The document is the most sustained defence and exposition of the dissident position in South Africa. There is absolutely no doubt that the President's flirtation with the dissident position has profoundly influenced, and many would say retarded, the implementation of effective government policy on AIDS in southern Africa.

If that is so, it is a tragedy of massive proportions because of the scale of infection, the scale of illness, the scale of mortality in South Africa. And in this AIDS denial is unlike the holocaust denial position, which has remained at the fringe of all intellectually and governmentally respectable debate. (Except, I suppose in some anti-Zionist circles in the Israeli-Arab conflict, presumably there may be some governmentally influential people who hold the conspiratorialist position on Jewish control of the world.) But this is the only clearly documented instance of a dissident position on such an important issue of social policy going to the very core of governmental leadership in a modern country. So that has been an enormous tragedy.

Fortunately, one month ago today, on 17 April 2002, the Government put itself behind a statement which for the first time was unequivocally incompatible with the dissident position. It endorsed the administration of anti-retrovirals on a large scale as a way of keeping people healthy, it committed itself to seeking reductions in drug prices, and to the rollout of a national program to prevent vertical transmission of HIV.

Other countries in southern Africa have high rates of infection – Botswana and Mozambique, for example, have higher rates of infection than South Africa. Are their governments toying with the dissident position, too?

No. The President of Botswana, President Festus Mogae, has committed himself to a national program of anti-retroviral provision in the public sector. The President of Namibia has underscored the importance of lowering drug prices in order to get broad-based anti-retroviral access.

Is the government's involvement in AIDS denial politically advantageous?

The dissident position isn't a vote-getter, I don't believe so. The populist organisations advocating treatment have revolutionised the way that civil society responds to government in South Africa, and have done so over the last few years. And clearly there's a deep sense in the townships and the rural areas that the government must act on AIDS.

I would say that the dissident position has been largely more attractive within government itself because of the leadership endorsement it has been given. I do think that the dissidents' re-stigmatisation of HIV transmission – as being somehow sexually shameful – has certainly led a lot of African intellectuals to ask questions about the epidemic: why is it in central and southern Africa a heterosexual epidemic and nowhere else in the world? As yet, of course – wait for India, wait for Russia. Nevertheless, I don't think that outside those circles the dissident position has any traction.

There's a cost issue here, too. If five million South Africans are HIV positive, and if the South African government committed to treating them all with anti-retrovirals, the expense would be astronomical. Is this making AIDS denial more attractive to the government?

AIDS denial takes many forms. AIDS dissidence is only the most extreme and the most destructive form of AIDS denial. Denial in its lesser forms entails postponement, turning one's eyes aside, failing to absorb the horrible truth. So I do think there is an element of ordinary denial in AIDS as well, in that accepting the facts places such a horrendously burdensome agenda on government that one might prefer to find some explanation that doesn't involve the cost, the extent of governmental commitment, the extent of governmental action, the extent of governmental urgency that AIDS would otherwise require.

Some South African companies – particularly in the mining sector – are having to respond to AIDS. Some

employee populations are up to 40% HIV positive, and some companies are starting to provide subsidised or free anti-retroviral treatments to their employees. Are private responses to AIDS likely to fill in where the government has failed?

Because of what was until 17 April 2002 governmental paralysis for two-and-a-half years on AIDS, there is no doubt that the responses of the nonprofits, non-governmental organisations, community organisations, trade unions and churches became primary. Leadership was foisted upon the corporate sector because of governmental inaction. And of course within the NGO sector itself there has been an enormous commitment, an enormous energy, an enormous inventiveness shown on AIDS. That certainly has happened.

But with 40% unemployment in South Africa, can private sector responses have an overall effect?

If you ask whether reaching only some people – those who aren't in the inaccessible rural areas, who aren't unemployed, who don't have access to our relatively rudimentary public health services – if you ask if that's making an overall impact, I say it is. If you're reaching only some people, you are nevertheless having an overall effect. If you're not reaching the others, you have to commit yourself to reaching them also. But start somewhere – don't make the better the enemy of the good. I say this because the scale of the problem is so awesome that committing oneself only to an abstract 'overall effect' could become totally paralysing.

Anyhow, when you talk about overall effects you have to start with an individual. I am a part of an overall effect. I fell ill with AIDS twelve-and-a-half years after infection with HIV. I was very seriously ill in October-November 1997. I started on a program of anti-retroviral treatment, and it is now four-and-a-half years later. I am a classic success story of anti-retroviral treatment. I work a 16-18 hour day some days, I am intensely involved not only with my judicial work but with a range of other projects.

So you've got to start somewhere and if only one other person has the benefits and privileges that I have then I think that is a result worth attaining. You've got to start within the churches, you've got to start within the trade unions, you've got to start within the employment sector. Every life saved to me is an overall impact.

The government's recent change of heart on anti-retrovirals is certainly a move in the right direction, but is there still work to be done here? Is the fight against AIDS denial simply over?

No. There is absolutely no doubt that the leadership endorsement of parts of the denialist position has had an impact on behaviour amongst ordinary people in South Africa. People who work in prevention in the townships, in the suburbs, in the cities have reported that many have adopted the denialist position as justifying a refusal to follow safe sex. So AIDS denialism in its most extreme form becomes an endorsement of someone's own lesser forms of denial.

But I do believe that we are on track now. I am an optimist. I have been an optimist about South Africa from the start. Racially, governmentally, constitutionally, legally, and on AIDS too I'm an optimist. And I think that the 17 April statement gives us real cause for optimism.

As a Justice of the Supreme Court of Appeal, you have life tenure. This makes it possible for you to speak freely on this issue where perhaps others cannot – but this sort of speech is certainly unusual among judges. How do you square your issue advocacy with the importance of judicial neutrality, or the appearance of judicial neutrality?

I like my job as a judge and I don't particularly like being controversial. Generally, I

think it is important that judges should be reticent on major issues of social policy. There are many good reasons for their being so. Under apartheid, judges were criticised for keeping quiet. But we now have a constitutional framework that ensures democracy and ensures a commitment – by no means already realised, but a commitment – to equality and justice and human dignity. So one would expect judges to be far more reticent about speaking out about social policy.

But on the AIDS issue I have felt that I had to speak out because of my personal involvement. I feel as if I've quite literally been given my life back by anti-retroviral treatment. And my treatment comes to me as a privilege of my position within an extremely unprivileged society. To me the prospect of any unnecessary HIV infection, of a single unnecessary death, feels like a personal challenge, a personal bell tolling for me. So I have felt compelled to speak out on AIDS, and to speak out not only about the inequities of international pharmaceutical drug pricing but also about the government's paralysis and failure until recently to move on a principled or rational basis.

So is it justifiable for judges in general to engage in issue advocacy? Where is the limit?

No, I don't think it is generally justified, and the limits should be drawn quite narrowly. The intense mix of personal, historical and political factors is what to me justifies it here. You're talking about a national crisis where over the next ten years ten million people in southern Africa face death – and really, an agonising and ghastly death, which is what a death from AIDS is – if there isn't effective governmental and social intervention. I think I was impelled to speak out, and I will continue to speak out; I cannot be silenced on it. Amidst all this, however, I am still cautious about what I say. I have for instance been careful not to speak about pending court cases. I have also been careful not to become a talk-show, dial-a-quote sort of person. I've been careful to speak out on appropriate scholarly or formal occasions.

You are presently trying to impact public opinion and behaviour by speaking out on AIDS. Has that always been your approach?

I was deeply involved in AIDS policy as a lawyer, and I was walking around with this huge secret that I was living with HIV myself. I knew that at some stage I would have to, and wanted to, integrate my public and private capacities on this issue. And the opportunity came which I felt impelled to take two years ago. That was when I was interviewed for a Constitutional Court vacancy by the Judicial Service Commission, I made a public announcement about my HIV status. And at the time I thought that other people would follow me. I thought there would be cabinet ministers, entertainers, members of Parliament, soccer stars … but it didn't happen.

Part of the reason it didn't happen is that President Mbeki in October 1999, six months after I went public, first started his public flirtation with the dissident movement. I believe that inhibited enormously the levels of public disclosure in South Africa about HIV status, and I think it set us back many years.

So we still don't have any member of Parliament who has publicly spoken out about living with HIV or AIDS. One member of Parliament has spoken out about her daughter's status (with the daughter's consent). But we don't have members of Parliament, members of provincial legislatures, of Cabinet, leaders in government service, pop stars, entertainers, sports stars – we don't have any such people who have spoken out about their HIV status.

To be clear, is there any possibility that these classes of people are entirely HIV negative?

No. Parliament is very representative of the

population as a whole. So you would expect in Parliament for there to be at least 40-50 people who are HIV positive, and in the cabinet you would expect there to be three or four people who are living with HIV or AIDS.

Would you have an obligation to recuse yourself on cases related to AIDS?

No. Not in general. I would certainly recuse myself on anything related to AIDS treatment issues – any case against the government or a pharmaceutical company related to AIDS treatment. But AIDS discrimination generally? No, because I have not expressed any views that have been unusual or controversial or even decidedly emphatic about AIDS discrimination. Similarly with equality issues relating to a person living with disability or with AIDS, or for the same matter about sexual orientation. I would no more be required to recuse myself on such issues than a black person on a racial issue, or a woman on a gender issue.

Cases relating to AIDS are not uncommon now, given the breadth and depth of the issue here. Recently, the Constitutional Court ordered the government to supply certain anti-retroviral drugs to HIV-positive pregnant women.[1] Where does the legal profession fit into the AIDS issue in South Africa?

That question takes us to the heart of South Africa's history as a nation under law. What was unique and iniquitous about apartheid wasn't so much the scale of its barbarism – because how do you weigh up a pernicious system of racial oppression against one million deaths in Biafra or 800,000 deaths in Rwanda? What was pernicious about apartheid was that it was a legally regulated system. The law was used to subordinate human beings, to deprive them systematically of their dignity. And the paradox of South Africa's democratic transition is that it is the law that has become the foundation of our constitutional and democratic commitment.

Under apartheid the ideas of law and justice were kept alive for democracy by activist challenges in the courts. ANC guerrillas were defended under apartheid's trial courts; trade unions used the law; community organisations used the law. There were interstices, there were spaces that could be and were exploited – for example, conscientious and religious objectors, which was one of my fields of specialisation. That history, very importantly, didn't come to an end when apartheid ended. In fact, activist organisations in the gay and lesbian movement, in the land justice movement, and in treatment action have reclaimed the moral space, and they have done so by bringing court cases. By active, creative public interest lawyering.

So that is the most important and interesting thing about the Treatment Action Campaign's case before the Constitutional Court, that they are using the democratic constitution in a way that historically is consonant with the way that anti-apartheid activists used the law under apartheid.

That isn't surprising, though. What is surprising is that the law hasn't been more used. The first group challenge under social and economic rights came before the Constitutional Court in April, 2000. That was six years after the Constitution came into force. So in fact the signal thing about it has been the relative *lack* of engagement of the law. I think the law has an enormous role to play, judges have an enormous role to play under the Constitution. We are only beginning to explore its role, and that's what makes it so exciting to be a lawyer in South Africa and to hold office under its Constitution.

1 *Minister of Health and others v. Treatment Action Campaign and others, Constitutional Court-CCT9/02, 4 April 2002, www.concourt.gov.za.*