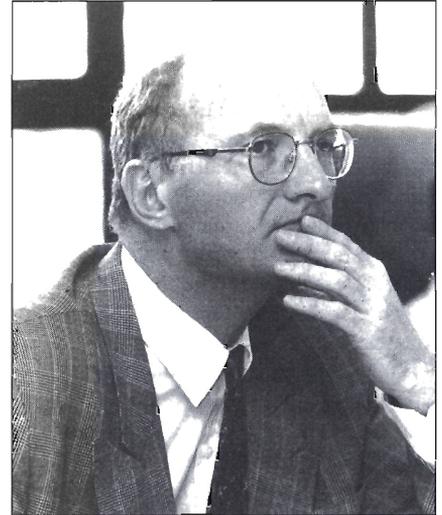


## Legislating for AIDS

Edwin Cameron

Supreme Court of Appeal



Judge Edwin Cameron

As a national issue, AIDS creates some painful resonances with apartheid. For one, it is the most pressing moral issue of our time. For another, as a basis of discrimination and exclusion it generally divides the affluent and the powerful in our society from the vulnerable and the dispossessed – the latter feel its most fearsome effects. Finally, it is an issue on which the capacity of our national leadership to speak with truth and integrity has most severely been tested.<sup>1</sup>

At least four to five million South Africans are living with HIV or AIDS.<sup>2</sup> According to Medical Research Council figures released in 2001, AIDS is already the main cause of death amongst young adults in our country.<sup>3</sup> Worldwide almost 40 million people (mostly poor sub-Saharan Africans) are living with HIV/AIDS. Twenty two million have died. This makes AIDS in simple terms the worst worldwide pandemic in 600 years.<sup>4</sup> Unless we act decisively, in the next decade as many as six million South Africans are fated to join the grim roster. Like apartheid, AIDS therefore poses profound challenges to our moral commitments. It calls our national leaders, legislators, judges, opinion-makers and lawyers as well as ordinary South Africans to truthful and vigorous responses.

In February 1996, when the epidemic was rapidly expanding, but had not yet reached its present mass scale, Justice Ismail Mahomed, then recently appointed to chair the South African Law Commission, approached me to lead a renewed initiative by the SALC into the law relating to HIV/AIDS. I felt doubly reluctant. On the one hand, I had been in the Johannesburg High Court for barely a year, and was still struggling to come to grips with the huge burden of commercial, constitutional and criminal work that judges there face. On the other, my own life encompassed a near-secret. For eleven years I had myself been living with HIV. For more than nine years I had known. I also knew that the next few years would be critical to my life and health. Ten years after infection the graph of those succumbing to a plethora of opportunistic diseases as the virus ravages the immune system rises sharply; by twelve

to fifteen years well over 90% of people with HIV have fallen severely ill or died. Could I, knowing my own vulnerability to imminent illness and probable death, and relying as I still was (outside a small circle of family, friends and trusted colleagues) on my entitlement to confidentiality, lead a major national project on AIDS law reform?

But Mahomed was not someone who readily accepted No, and I eventually agreed. I joined a powerful team (Anna-Marie Havenga, the SALC's formidably skilled and hard-working researcher, and Professor Christa van Wyk, Unisa's tough-minded AIDS expert and authority). I suggested some strong additions – Zackie Achmat, who would gain renown as a treatment activist, Bokkie Botha, an AECI executive who headed social policy for Business South Africa, Dr John Matjila, a community health specialist and HIV clinician from Medunsa, and Ann Strode, a human rights lawyer working with the Department of Health.

We set to work immediately. At Achmat's strategic suggestion, instead of focussing on vast and contentious issues that were likely to divide us, we produced within a few months unanimous recommendations for attainable legislative measures on critical but doctrinally uncontroversial issues.<sup>5</sup> These included

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condom standards,<sup>6</sup> universal workplace anti-infection precautions and safe disposal procedures for healthcare hazards,<sup>7</sup> and a draft national policy with guidelines for HIV testing.<sup>8</sup> The report was tabled in Parliament within record time, and on 18 September 1997 the National Assembly resolved that the government implement its recommendations urgently. That has been partly done.

Over the next five years four more reports followed. The second recommended a statutory ban on pre-employ-

ment testing for HIV.<sup>9</sup> The third, drafted under van Wyk's strong leadership when Nkosi Johnson was initially refused admission to a Johannesburg primary school because he had AIDS, proposed a national policy for schools outlawing unfair discrimination on the basis of HIV status.<sup>10</sup> The fourth recommended compulsory testing, at the instance of a sexual offence victim, though subject to strict confidentiality and procedural safeguards, of the alleged assailant.<sup>11</sup> The fifth and last – perhaps our most complex and detailed investigation – recommended against legislative intervention to create additional HIV-targeted statutory offences.<sup>12</sup>

In addition, our first report also focussed on practice regarding medical certificates for AIDS-related deaths. In our preceding AIDS discussion paper,<sup>13</sup> we had suggested amending the Regulations on the Registration of Births and Deaths 1992<sup>14</sup> published under the Births

and Deaths Registration Act 51 of 1992 so as to protect privacy in relation to HIV/AIDS while at the same time establishing a reliable mechanism to collate essential epidemiological information. Responses alerted us to the fact that the Departments of Health and Home Affairs were already considering alternatives. We therefore hosted a workshop that reached consensus that death registration should incorporate two separate aspects. First, a public notification of death containing the deceased's full particulars but otherwise specify-

ing only whether the death was from natural causes or not; and second, a further confidential itemisation fully specifying the direct and underlying cause/s of death which would be available for medical research, health care modelling and private contractual purposes. The Department of Home Affairs subsequently amended the Regulations in accordance with this consensus.<sup>15</sup>

The Commission's initiative has run its course. More important issues now dominate the national and international debate – most acutely how to provide affordable treatment and medical management to millions of South Africans and others in the developing world. They face death if untruth, ineptitude and paralysis continue. The scientific, medical and epidemiological truths about HIV have been exhaustively and incontrovertibly established. Those who would deny the facts threaten the lives and well-being of many millions of South Africans. HIV is a virally specific condition that is mostly sexually transmitted. If uncontained it almost certainly results in progressive destruction of the human immune system, leading to near-certain death. But the most important fact about AIDS is that it can now be successfully managed.<sup>16</sup>

AIDS is not dead. But the notion of AIDS as an incurable fatal condition is. In July 1996 – just months after Mahomed approached me about the SALC investigation – a momentous breakthrough was announced. Successfully administered combinations of anti-retroviral drugs can now completely immobilise the virus within the human body. That is why I am alive today. Against hope, I fell severely ill with AIDS in October 1997. I was fortunate enough to be able to afford the then enormous expense of the anti-retroviral drugs (they have since come down in price by over 90%). Without them, I would have been dead within about three years. Instead, my recovery strengthened me to announce my condition at a Judicial Service Commission hearing in April 1999. Four and a half years after falling fatally ill with AIDS, I feel blessed with a full and active life. As a lawyer and a judge holding office proudly under one of the world's most visionary Constitutions, I ask myself what the law can do in an epidemic of such massive and devastating scale. Justice Ngcobo on behalf of the Constitutional Court has given us a clue:

"People who are living with HIV constitute a minority. Society has responded to their plight with intense prejudice. They have been subjected to systemic disadvantage and discrimination.

They have been stigmatised and marginalised. As the present case demonstrates, they have been denied employment because of their HIV positive status without regard to their ability to perform the duties of the position from which they have been excluded. Society's response to them has forced many of them not to reveal their HIV status for fear of prejudice. This in turn has deprived them of the help they would otherwise have received. People who are living with HIV/AIDS are one of the most vulnerable groups in our society. Notwithstanding the availability of compelling medical evidence as to how this disease is transmitted, the prejudices and stereotypes against HIV positive people still persist. In view of the prevailing prejudice against HIV positive people, any discrimination against them can, to my mind, be interpreted as a fresh instance of stigmatisation and I consider this to be an assault on their dignity. The impact of discrimination on HIV positive people is devastating. It is even more so when it occurs in the context of employment. It denies them the right to earn a living. For this reason, they enjoy special protection in our law."<sup>17</sup>

This eloquent passage summarises not only signal social truths about AIDS, but the Constitutional Court's approach to discrimination and stigma, and the role that our constitutional promise of equality for all must play in remedying those evils. As a nation, we have committed ourselves to the ideals of justice and equality and the progressive realisation of social and economic rights under the law. AIDS imperils that vision, but it also calls us most imperatively to its fulfilment.

### Endnotes

- 1 I discuss the triple AIDS crises of disease and death, management and leadership, and national truth-telling, in the Foreword to (2001) 2 *Law, Democracy and Development* vii, excerpted as an opinion piece in *Business Day* 25 October 2001, and available at <http://www.bday.co.za/bday/content/direct/1,3523,954454-6096-0,00.html>.
- 2 The UNAIDS figures for South Africa are available at [http://www.unaids.org/hivaidsinfo/statistics/fact\\_sheets/all\\_countries\\_en.html](http://www.unaids.org/hivaidsinfo/statistics/fact_sheets/all_countries_en.html) (South Africa).
- 3 Medical Research Council "The Impact of HIV/AIDS on Adult Mortality in South Africa" by R Dorrington and others, released in September 2001, available at <http://www.mrc.ac.za/bod/index.htm>.
- 4 *Consensus Statement on Anti-retroviral Treatment for AIDS in Poor Countries* by individual members of the Faculty of Harvard University, March 2001. Dr Anthony Fauci of the United States National Institutes of Health describes AIDS as "one of the most destructive microbial scourges in history."
- 5 All the South African Law Commission's reports are available at <http://www.law.wits.ac.za/salc/salc.html>

- 6 The Department of Health appears to have responded to the SALC's recommendations by maintaining continuous supervision of condoms standards in the light of the criteria suggested.
- 7 In November 1999 the Department of Labour published for comment Draft Regulations for Hazardous Biological Agents (Government Notice R 1248 in Government Gazette 20555 of 1 November 1999), incorporating the SALC's recommendations and on 27 December 2002 the Regulations for Hazardous Biological Agents were promulgated (Regulation Gazette 7233, Government Gazette 22956).
- 8 The Department published a draft policy, based on the Commission's recommendations, for public comment on 10 December 1999 (Government Notice R 1479 in Government Gazette 20710 of 10 December 1999). The published draft largely adopted the Commission's HIV testing policy but added emphasis on the need for pre- and post-test counselling. Comments have been processed and promulgation is expected shortly.
- 9 The SALC recommendations on pre-employment testing were partially embodied in the Employment Equity Act 55 of 1998 (see ss 5, 6 and 7; s 5 expressly prohibits unfair discrimination against an employee in any employment policy or practice on the ground of HIV status; s 7 prohibits testing an employee – including a job applicant – for HIV unless declared justifiable by the Labour Court). Other related developments include the enactment of the Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000 (see ss 5, 6, 9, 24, 25, 28, 34 and the Schedule; s 9 expressly prohibits unfair discrimination on ground of disability (which may include HIV and AIDS), while s 34(1) provides specific directive principles on HIV/AIDS), and the Medical Schemes Act 131 of 1998, which provides specific protection against exclusion from benefits to employees and other persons with HIV/AIDS.
- 10 General Notice 1926, Government Gazette 20372 of 10 August 1999. The Department of Education adopted the Commission's proposed policy almost exactly. The main difference is that the promulgated policy will also be applicable to *educators* in public schools, and to *students and educators in further education and training institutions*. For reasons set out in the Third Interim Report the Commission's proposed policy was intended primarily for *learners* in public schools (see fn 210, par 6.25 and 6.70 of Third Interim Report on Aspects of the Law relating to AIDS).
- 11 The Report was tabled in Parliament on 26 June 2001. Legislative attention is expected during the 2002 parliamentary programme.
- 12 The Report was tabled in Parliament on 13 September 2001.
- 13 SALC Discussion Paper 68.
- 14 Government Notice R 2139, Government Gazette 14182 of 9 September 1992.
- 15 See the Third Amendment of the Regulations on the Registration of Births and Deaths 1992 Government Notice R 879, Government Gazette 19006 of 3 July 1998.
- 16 These facts are authoritatively set out in the Constitutional Court's judgment in *Hoffmann v South African Airways* 2001 (1) SA 1 (CC) paras [13-15].
- 17 *Hoffmann v South African Airways* 2001 (1) SA 1 (CC) para [28].