

University of Stellenbosch, Faculty of Law
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***'LEGAL AND HUMAN RIGHTS RESPONSES TO
THE HIV/AIDS EPIDEMIC'***

Special lecture

by

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Supreme Court of Appeal

1. It is a great pleasure to be here tonight. As an oud-Matie law undergraduate, I count it an honour that Professor Sandra Liebenberg, Professor of Human Rights Law, has invited me back to speak in this venue. For me its memories are rich, intense and varied, since I made my first academic acquaintance with the law as a first-year student in this very room. And I am privileged to have a continuing academic association with the Faculty: your new Dean, Professor Marius de Waal, was my principal co-author in the fifth edition of *Honoré's South African Law of Trusts* (2002) – to which he brought his meticulous care, generosity of both spirit and scholarship, and his intellectual distinction.
2. With tonight's occasion in mind, I have prepared a detailed exposition of legal and human rights responses to the AIDS

epidemic in this country over the past fifteen years. This paper is available on the Stellenbosch law faculty's website.

3. But I do not want to burden our time together this evening with the grey detail of legislation, legal measures and lawyers' debates. Instead, I want to try to place all those laws and measures and debates in an overall perspective within the AIDS epidemic. How do we understand the epidemic and the momentous challenges it poses to us?
4. From the first official reports of AIDS cases at the end of June 1981, nearly 25 years ago, it has been plain that AIDS would not be 'just' a disease: it would not be analysed and treated according to straightforward scientific and medical precepts as a bodily manifestation of a viral infection.
5. Instead, its management would be beset by political controversy, clouded by stigma, burdened by moralistic overlay and obscured by pseudo-scientific misconceptions.
6. A quarter of a century later, this is regrettably still the case. Yet AIDS remains a disease. Beyond the stigmas, the metaphors, the constrictive moralising, and the perverse epistemologies, it *is* after all the bodily manifestation of a viral infection.
7. To manage its effects, we must surely first understand its environmental and social determinants: that is elementary about

all disease. But with AIDS, the very problem has been that all too often those determinants have been obscured by overlays of moralism, misconception and ignorance.

8. The history of AIDS can in many ways therefore be seen as a struggle to assert the primacy of the material facts of physiology and virology in managing the disease, over the inhibiting and damaging interposition of social conceptions of the disease.

9. In this sense, the history of the epidemic can be seen as a struggle for the 'normalisation' of the disease:

- a struggle for compassion against condemnation (represented in the struggle against stigma);
- a struggle for equity and justice against material dispossession (represented in the struggle for treatment for those dying of AIDS);
- a struggle for the pre-eminence of principles of medical management in the diagnosis and treatment of HIV, as opposed to the continued 'exceptionalisation' of AIDS (represented in the struggle for the 'medicalisation' of its clinical management) ; and
- a struggle, above all, for rationality against irrationality in government and public response to the disease (represented

in our country by the struggle for scientific truth against the dissident ideology of AIDS denialism).

10. These four terrains in which the battle for normalisation of AIDS has been fought are inter-connected, and stigma lies at the heart of each.

Stigma

11. Stigma is a visible impress of social revulsion and disapproval against a group or person or condition. It is no exaggeration to say that AIDS is one of the most stigmatised diseases in human history. More than leprosy and tuberculosis, more even than the Black Death in Europe in the 14th century, whose casualties were reviled because of understandable fear of contagion, AIDS is reviled even though it is not contagious. It is reviled because those who have it are not merely blamed for their own condition, but condemned for having it.
12. The reasons are as patent now as they were a quarter of a century ago:
 - AIDS is a mostly sexually-transmitted disease in a world that still treats sex as shameful;

- HIV infection is incurable, and for most still fatal, in a world that all too understandably treats death and bodily decay with horror; and
- The epidemic's effects have disproportionately burdened poor and socially marginalised groups – gay men in the affluent 'North'; black Africans in the resource-deprived 'South' – in a world where social power and wealth still translate with almost chilling exactness into access to health and to life.

13. The enacted manifestation of stigma is discrimination. South African law has responded with a fair proliferation of statutory measures to protect people living with HIV/AIDS from discrimination. I examine them in detail in the paper prepared for this occasion. They are the brightest testimonial for government's response to the epidemic since 1994.

14. The rationale for such measures was lucidly explained in the Constitutional Court's commanding first decision on AIDS discrimination, *Hoffmann v South African Airways* the Constitutional Court. In the words of Justice Ngcobo:

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.¹

15. The struggle against stigma is in essence a struggle to normalise the disease by freeing it from the overlays of blame and condemnation that inhibit rational and compassionate treatment of its physiological and social manifestations.

16. It is very far from clear that in South and southern Africa today we are winning the struggle to normalise AIDS over

¹ 2001 (1) SA 1 (CC) para 28.

stigma. This is in part because the struggle is not just against stigma's external manifestation, but against its internalisation in those who have, or fear they have, HIV: the shame and disempowerment and self-disabling ignominy they all too often feel.

17. I experienced that shame myself, when I was diagnosed with HIV in the dark days before it could be treated, and during the years when I kept my infection a deathly secret. Even though I was an openly and proudly gay man when diagnosed, I thought that my shame related to my homosexual exposure. That was wrong. The shame is no less amongst heterosexuals in the mass epidemic of heterosexually transmitted HIV in Africa. I witness it in too many people around me who are too hesitant, too scared, too fearful, too ashamed, to claim help and treatment even where it is offered.
18. The fact that AIDS can now be medically managed holds promise of diminishing the effects of stigma, since it deals with its one source (death and debilitation); but not of eliminating it, since its other source (sexual transmission) remains. There a considerable struggle continues.
19. AIDS will not be 'normal' until no one feels inhibited from seeking treatment and support because of guilt, self-blame, embarrassment or fear of social disgrace. That will be achieved

only when we have understood and effectively addressed the shame that derives from sexual transmission.

20. That shame was given unexpected reinforcement by the proponents of AIDS denialism, who sought to suggest that the medical model of HIV, premised on sexual transmission, involved a racist condemnation of heterosexual Africans' sex habits. This bizarre misconception has proved extremely damaging, and its effects in heightening stigma (as I indicate later) are still being felt.

Treatment

21. Effective treatment for AIDS was not available before 1996. But in that year dramatic breakthroughs in administering combinations of anti-retroviral medication were announced. These revolutionised the medical management of the disease. From being an invariably fatal condition, AIDS became clinically manageable: but only for those who had the money to afford the fantastically high cost of medication.
22. This was not because the drugs were expensive to produce. On the whole, they were not. It was because the corporations holding the patent rights to the drugs were determined to secure for their shareholders a maximum return, even though doing so

meant their garnering billions of dollars in profits while millions of people too poor to pay would die unnecessary deaths.

23. Ethically this was monstrous. Yet many governments and international organisations around the world, including on our own continent, either accepted it as innate to the structure of the globalised economy or considered that the ideology of corporate entitlement was invincible.
24. It took the principled fervour and the moral outrage of treatment activists around the world to challenge the presuppositions that made an iniquity on this colossal scale capable of being countenanced.
25. A heroic struggle ensued, in which South Africa's Treatment Action Campaign played a signal role, both locally and internationally, in shaming international drug companies into lowering their prices.
26. What was unimaginable just four or five years ago became possible through unwavering challenge to corporate practice and thinking.
27. The struggle for treatment access was about practical matters: the irreducibly critical questions of life and bodily health. But it achieved success because it succeeded in re-ordering conceptions of normality in treatment for poor people.

28. All too recently a world in which poor people are entitled to treatment for treatable disease seemed not only unattainable, but unimaginable. That this is no longer so is because the principled struggle of the treatment activists has re-defined 'normalcy', and admitted within its confines the claims of poor people with AIDS.
29. The implications stretch far beyond AIDS. The struggle is for a world in which it is accepted as proper and usual and appropriate that those with treatable medical conditions do receive treatment; that this is neither a gratuity nor an indulgence, but a moral right, properly exigible through governmental and organisational action.
30. Many issues remain. AIDS can be a difficult disease to treat. It requires the effective distribution of an appropriate range of anti-retroviral drugs; proper patient examination and assessment, with the careful employment of blood monitoring procedures; counselling and empowerment of the patient through information and treatment literacy; and thereafter careful medical monitoring to assess drug tolerance and possible abreactions and toxicity. And after all this, patient compliance is also critical.

31. But compared with the prospect of an inevitable, agonising and premature death, these difficulties can and must be managed. They are being managed. And we must not underestimate what has been achieved in making them so. The activist struggle has achieved a world in which AIDS has been so far 'normalised' that an international consensus as to the necessity of treatment exists. That is a signal achievement no less in moral than in practical terms.

'De-exceptionalisation' of AIDS

32. In public health emergencies involving the outbreak of infectious disease, it is usual to apply certain well-known rules of disease management and containment. These include essentially coercive measures that are designed to contain the disease outbreak: identification, isolation, confinement, partner tracing and notification, and compulsory reporting of diagnosed cases.

33. Though HIV is not contagious, it is infectious, and for much of the first quarter century of the epidemic's history there has been an occasionally passionate debate about the extent to which it is appropriate to apply the ordinary principles of public health regulation to its management.

34. For 25 years, by widespread (though not universal) consensus among public health specialists, AIDS has been treated as exceptional. The consensus arose because of the two signal issues marked earlier – the enormous stigma attending AIDS, and the absence of treatment – together with certain additional factors specific to the disease. These were the long latency period of the virus, and the fact that it was mostly transmitted during intimate consensual conduct between adults in private.
35. In addition, although HIV is infectious, it is a weak pathogen which is not easily transmitted. For human-to-human transmission to occur requires sustained (even somewhat determined) exposure to infected bodily fluids. In addition, detection of HIV infection in its early stages is not always easy.
36. For all these reasons, the AIDS epidemic was treated in ways signally different from previous public health emergencies. It was accepted that it was futile to try to identify those with HIV and impossible to seek to isolate them. Partner tracing was rejected as not only unacceptably intrusive, but an unwarrantably colossal task.
37. The enormous stigma associated with AIDS made it too risky to contemplate most systems of reporting, since the risk of

confidentiality breach was too high, and its consequence too injurious.

38. Coercive measures were seen as likely to be counter-productive, since experience showed they would almost certainly engender reticence, avoidance and denial amongst those most at risk of infection, placing the public at even greater risk of its further spread.
39. The pursuit of public health goals therefore led to unusual treatment for AIDS. At the core of this approach was the well-known 'AIDS paradox': the recognition that protecting the rights of those with HIV was not inimical, but complementary, to disease containment. Coercive measures were recognised as not merely needless punitive: they put the very public they were designed to protect at unnecessary risk of further infection.
40. But acceptance of this paradox has led to a further paradox. One of the ways in which those living with HIV were protected was through elaborate insistence on measures to ensure confidentiality.
41. In tandem with this, diagnostic procedures in the healthcare setting were hedged around with special rules for HIV. Consent to HIV testing could not be general: it had to be specific. And it

could not be implicit: it had to be express. And the momentous implications of diagnosis had to be carefully canvassed with the patient both before and after the test.

42. These protections were designed for a world in which stigma caused death, and in which protection from its effects could often be secured only by protecting the patient from unnecessary HIV testing, whose only product, all too often, would be victimisation.

43. They were designed for a world in which, while the opportunistic infections associated with HIV could be palliated, little could be done to halt the assessment with death that infection entailed.

44. All that has changed. Because of the activists' struggle for the normalisation of AIDS, treatment is now widely available, even in many resource-poor settings. And it is becoming more and more accessible.

45. And where treatment is available, signs increasingly suggest that the exceptionalisation of HIV infection in the healthcare setting may be impeding its effective management.

46. This is because many people, offered the choice of diagnostic procedures whose exceptional and unusual nature is emphasised, prefer not to be tested. The safeguards intended

for their protection reinforce their fears, and all too often they accentuate also their inner disavowal of entitlement to betterment. They prefer to ascribe their symptoms to causes other than HIV, when all too often the routine administration of a test will confirm the opposite, and open the way to effective management of their condition.

47. This is the new paradox that has emerged: that the exceptionalisation of HIV, designed to protect people with HIV from needless discrimination, may constitute a barrier to justice now that effective treatment can be offered.

48. This new paradox has engendered a debate within the human rights community about the extent to which exceptional protections for HIV testing in the healthcare setting should be relaxed.

49. Clearly no patient should ever be coerced into a diagnostic procedure against her or his will. This principle is particularly important where the likely consequence of diagnosis continues to be ostracism, discrimination and isolation.

50. But where diagnosis could lead to treatment, to the preservation of the patient's life, where continued ignorance will surely hasten death, the healthcarer's duty of beneficence to the patient must demand that accurate diagnosis should be

encouraged. Where possible, it should be a routine and uncontroversial element in the treatment process.

51. Where treatment can be offered to the patient, the aim should therefore be to make HIV testing normal, not abnormal, and the exceptional procedures and barriers surrounding it should be diminished rather than preserved.
52. Within this debate lies a critical issue at the heart of the struggle for the normalisation of AIDS. In what sense can we reliably claim that the disease is special? Nothing about AIDS – the disease itself, or the epidemic – is intrinsically or conceptually exceptional. Its exceptional features (the extent of the pandemic; its destructive impact; the stigma surrounding it; the discrimination) are purely strategic and incidental.
53. In principle, therefore, all strategic responses to AIDS should be aimed at normalising the treatment of HIV, not only socially, but more especially within the healthcare setting.
54. The great risk is that the exceptionalisation of the disease, which was designed to protect, will now harm those with HIV. That would be more than an irony. It would be a destructive consequence that no one of us should be willing to countenance.

*AIDS denialism and the normalisation of the epidemic in
South Africa*

55. In South Africa, the most unexpected and tragic obstacle to the normalisation of AIDS has been the struggle to secure a place for anti-retroviral treatment in the overall official response to the disease.
56. For centuries, health specialists have been profoundly aware of the critical role environmental vectors play in the spread and onset of disease: how poverty, malnutrition, insanitary conditions, unsafe drinking water, and exposure to other harmful pathogens increase the risk of any specific infection and hasten its progression.
57. In the management of AIDS, these insights led to the early recognition, by experts such as Dr Jonathan Mann, that Africa's ills in particular required a holistic response, and that disease-specific interventions had to be promoted within the context of a larger response that attended to the environmental and social setting and to the physiological vulnerabilities of those infected with HIV and falling ill with AIDS.
58. When the dramatic success of anti-retroviral medications in treating AIDS became known in the mid-1990s, it was beyond debate or doubt that nutrition and health supplements and a

whole-lifestyle response to immune system care was an indispensable part of their administration.

59. The only obstacle to the normalisation of the disease from a treatment perspective seemed to be medicine pricing and availability, and it is to the question of corporate profits and practice that the activists accordingly turned their attention.

60. Yet, astonishingly and tragically, what became controversial in South Africa was whether anti-retroviral treatment had any place at all within a 'holistic' response to the epidemic.

61. A new and quite unexpected front was opened in the battle to normalise AIDS: that of persuading government that anti-retroviral treatment had to form a part of its overall response to the epidemic.

62. The grievous episode of denialism constitutes the most damaging interposition of unscientific misconception about AIDS in the epidemic. This started in late 1999, when President Mbeki seemed to give public endorsement to dissident scepticism about –

- the existence and nature of HIV,
- whether testing for it had any point, and
- (most radically) whether HIV was the cause of AIDS.

63. While the President has never publicly stated that he believes that HIV is not the cause AIDS, he has never publicly said that he accepts it is. Nor has he ever unequivocally renounced those dissidents who claim to have influenced his thinking against conventional scientific approaches to the causes of and treatment of AIDS, and who continue to invoke his name and authority.
64. The consequence for our national response to AIDS has been agonising. The spectre of AIDS denialism has inhibited, hindered, held back and obstructed it, at terrible cost in lives and suffering.
65. Light seemed to have broken in August 2003, when Cabinet committed itself for the first time to providing anti-retroviral medication on a large scale through the public health care system. In November 2003 the Minister of Finance announced a generous medium-term government spending framework for HIV and AIDS, and Cabinet then approved a national treatment plan.
66. These breakthroughs, too, were in no small part due to the efforts of the treatment activists, mainly the Treatment Action Campaign and the extraordinary alliance they forged with other civil society organisations, including churches and trade unions.

Cabinet members and political leaders who worked for a rational approach to the epidemic will no doubt one day also be recognised, for history's record will not be impassive.

67. Since the public provision of anti-retroviral medication began, some 60 000 people have been able to access it through the public health services. This is 60 000 more than would have had access if denialist scepticism about anti-retroviral treatment of AIDS had prevailed.
68. Yet it seems that the agony that denialism inflicted has not yet left us. We still lack a concerted, unified, unambiguous national leadership position on AIDS. What is more, the health minister seems to associate herself with messages about clinical responses to AIDS that confuse and inhibit rational decision-making. And she seems to lend support to individuals who attack and obscure the scientific premises of the medical treatment of AIDS.
69. This was brought home to me in a shocking way recently when a young professional man in an executive position in a large governmental structure came to see me at my home. Last year a sibling died of what he described to me as AIDS-related causes. Recently he was himself twice ill with pneumonia, and his CD4 count is so low that his immune system is scarcely

functioning. Why, given his high income and his stout job protections, is he not on anti-retroviral treatment? He told me that the head of his structure's wellness unit, a professional nurse, had counselled him away from anti-retroviral treatment, and toward natural remedies of the sort the health minister advocates.

70. There seems little doubt to me that if this advice continues to guide his choices, he will not live for long, and I felt constrained to tell him so. What is troubling is that confusion and misdirection of this sort seems to be fairly widely disseminated. Its cost in human life cannot be calculated.

71. The unavoidable conclusion is that the denialist episode in our national history continues to impede the normalisation of AIDS.

72. We cannot wish it away by suggesting that denialism sought to emphasise only the importance of nutrition, or that its concern was only to underscore the potential toxicity of anti-retroviral treatments. To portray it thus is reminiscent of those who claim that apartheid was merely about preserving South Africa's infrastructure from the risk of post-colonial collapse that occurred elsewhere in Africa. It is as misconceived, for it disregards the suffering caused by both events, and it is as

damaging, since it threatens future planning by inhibiting proper responsibility and accounting for the past.

73. AIDS denialism sought to controvert the scientifically and medically incontrovertible in regard to AIDS – that AIDS is a virally caused, mostly sexually transmitted disease, for which – in more than 90% of cases – anti-retroviral medications offer successful treatment.

74. At the same time, denialism supposedly endorsed propositions about the environmental and social vectors and precipitants of disease, and their impact on treatment (including the necessity for a holistic approach), that were so self-evident that no sensible person had ever sought to put them in issue.

75. AIDS denialism was a hideous and costly mistake. Its effect in delaying a rational, coherent response to AIDS in South Africa may be counted in the lives unnecessarily lost while government evaded and avoided the issues.

76. The fearsome suspicion that denialism may still be inhibiting the vigour with which the public provision of treatment is occurring must raise continuing questions about its impact. Government will be able to deal with the epidemic with effective moral authority only once it has purged itself of the intellectual and moral burden of denialism.

77. South Africa faced its previous pre-eminent moral challenge – the racist oppression of colonialism that apartheid most viciously embodied – with resilience and courage. Above all, it faced it with the moral clarity and purity of vision that produce the capacity for resolute action.
78. South Africa desperately needs the same clarity and purity and resolve in relation to AIDS. If we are to normalise the epidemic, and treat it as the bodily manifestation of a viral particle, AIDS denialism and its effects must first be accounted for, acknowledged, disavowed and expunged from our national life.
79. It may be that a formal process of examination and accounting, similar to that undertaken by the Truth and Reconciliation Commission in relation to apartheid, will be necessary to achieve this.
80. What is clear is that until our leaders express clarity on the causes of and due treatments of AIDS, South Africa can not take its rightful place as a moral leader in Africa's struggle to secure justice for the tens of millions living with the disease – most urgently in the continent's struggle for funding through the Global Fund on AIDS, TB and Malaria.

Conclusion

81. Key to the normalisation of AIDS are law and legal regulation. Legal protections against discrimination are an indispensable part of the battle against stigma. Changes in approaches to patent enforcement have been vital to treatment access. The legal protections burdening HIV testing require reconsideration and reform. And it was the courts who forced the government, in the litigation concerning the prevention of perinatal transmission of HIV, to embark on the rational road that embraced anti-retroviral provision.
82. But the battle to normalise the disease lies in our minds and our hearts. AIDS is a heavy consciousness, burdening our beings and exacting a daily price in grief and bereavement and continuing mourning.
83. But in the end AIDS exacts its toll on human bodies. The struggle for the normalisation of the disease involves a commitment to moral, practical and rational premises in action. We have undoubted power for such action. We only have to assert the primacy of the material and the rational over the shadow of stigma and misconception. For that is where the future struggle about AIDS lies: a struggle within ourselves to normalise not so much the disease as our responses to it – a

struggle for rationality and compassion over fear and condemnation and ignorance.