



SEMINAR: Passing Judgment: *The Role of Bioethics, Public Health Ethics and Human Rights in Policy*

Hess Commons
722 West 168th Street
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Mailman School of Public Health

Thursday 18th October 2012, 17h00 for 18h00

KEYNOTE ADDRESS

by

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* I am greatly indebted to my foreign law clerk, Pia Dutton, for energetically researching this talk, and even more energetically engaging with the ideas for it.

AUTONOMY, DIGNITY AND RIGHTS – A JUDGE’S REFLECTIONS

ABSTRACT: Internalisation of stigma in people living with and at risk of HIV remains so powerful that it demands a re-think of applied notions of autonomy in informed consent. In a mass epidemic of HIV, where treatment is publicly provided, internalised stigma makes it imperative now to move without more beyond physician-offered HIV testing and treatment, to physician-recommended or –urged testing and treatment.

1. It is a great honour to give the keynote on the occasion at which the Centre for Bioethics is inaugurated as a Collaborating Centre with the World Health Organisation. In expressing my pleasure at being invited, I want to pay particular tribute to Professor Ronald Bayer. He has been in the Mailman School of Public Health for almost 25 years. It is not only his energy, but his distinction as a scholar, and his stature as a human being, that have created this occasion.
2. I know this from his impact on my own life and thinking:

- i) Ronald Bayer's article in the 1991 *NEJM*, "Public Health Policy and the AIDS Epidemic - *an End to HIV Exceptionalism?*"¹ made a deep impact on my thinking about the epidemic. I still remember the vivid freshness with which it struck me when I read it. It gave me my first understanding of the historical background to the special management measures for dealing with AIDS – and the fact that they derived from contingent circumstances that were changeable. In 1991, those changes had not yet happened. They would not happen until effective antiretroviral (ARV) treatment became widely available five years later.² But Bayer's article heralded them. It profoundly influenced my understanding of the disease and its management. That impact is evident in what I say tonight.
- ii) Second, on an even more deeply personal note, Professor Bayer interviewed me in 2004 for his book "Shattered Dreams"³. During the interview, something happened that had never taken place before and has not happened since to me – I started weeping. So intense, so attentive, so informed, so empathetic, so deeply embracing were his questions that I surprised myself by finding tears issuing in full from my eyes. He remained respectfully, empathetically silent. If we weren't paying tribute to Ronald Bayer as an accomplished epidemiologist and ethical thinker tonight, we might have been doing so to him as a psychotherapist.
3. It is the influence of this man, both intellectual and personal, that has shaped the Centre, and that brings us all together at this event.

¹ Bayer, "Sounding Board: Public Health Policy and the AIDS Epidemic: *An End to HIV Exceptionalism?*", *New England Journal of Medicine*, 324: 1500-1504 (May 23), 1991

² UN World AIDS Day Report 2011, "How to get to Zero. Faster. Smarter. Better" available at http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/JC2216_WorldAIDSday_report_2011_en.pdf. The Report envisages a world in which there will be zero new HIV infections, zero discrimination and zero AIDS-related deaths. The Report also documents 1996 as the pivotal year in which ARV treatment became more widely available.

³ Oppenheimer and Bayer, "Shattered Dreams?: An Oral History of the South African AIDS Epidemic" *Oxford University Press* 2007

4. My theme is a personal reflection on autonomy, dignity and rights. Let me tell you what I'm going to say before I say it.
5. I argue that these last anguished three decades of AIDS have changed our world irreversibly. They have done so in three principal ways –
 - i) First, the relation between doctor and patient and subject and science;
 - ii) Second, public health, global justice, intellectual property rights and the morality of dying;
 - iii) Third – and this is my main theme – how the distinctive social and psychological features of HIV infection and of AIDS pose a challenge to received notions of autonomy, personality, exercise of choice and paternalism.
6. It has been more than 31 years since AIDS was first officially reported.⁴
7. In these three decades, the disease and the mass epidemic it has caused have irreversibly changed the way we think about illness, its management and those who discover and offer treatment.

The Doctor/Patient & Subject/Science Relation

8. The first way in which AIDS has changed our world is that it has wrought an irreversible alteration in the relation not just between doctor and patient, but between subject and science.

⁴ *MMWR Weekly* (1981) "Kaposi's Sarcoma and Pneumocystis Pneumonia among Homosexual Men – New York City and California", 4 July, 30(4); 305-308.

9. It is well documented, of course, that in the 1960s and 70s the ideas impelling the discipline of bioethics profoundly challenged the authority of physicians and researchers.⁵ The notion of consent to be treated and to be researched upon became pivotal.⁶ No longer was the authority of medicine or science sufficient to warrant interventions, procedures or investigations on a human subject.⁷ The subject had the right to know, to know fully, and to choose.⁸
10. AIDS radically accelerated this challenge to medical and scientific authority. The most immediate visible impact of the disease was on white middleclass, mostly self-identifying gay men on the east and west coasts of America, in Western Europe and in Australasia.⁹
11. It was precisely this demographic segment who had lived through an elated dozen years of elated personal expression, sexual freedom and

⁵ Macklin, "The Doctor-Patient Relationship in Different Cultures" in *Against Relativism: Cultural Diversity and the Search for Ethical Universals in Medicine*, Oxford University Press (1999). Macklin states that the commitment to bioethics and autonomy stems from a decided deficiency in rights of self-determination. She states that the evolution which took place in the United States began with early rulings (1914) requiring doctors to obtain consent of their patients and bled into the 1950s-70s with a series of "informed consent" cases. See also Callahan and Jennings, "Ethics and Public Health: Forging a Strong Relationship" *American Journal of Public Health* 2002; 92:169. Callahan and Jennings acknowledge an epidemiological "obstacle": "the difference between the individualistic orientation of bioethics and the population and societal focus of public health."

⁶ Bayer and Fairchild, "The Genesis of Public Health Ethics", in *Bioethics Reader, Editors' Choice*, Cahdwick, Kuhse, Landman, Schuklenk and Singer eds. (2007), Chpt 12 at p.191.

⁷ Ackerman, (1996) "Choosing Between Nuremberg and the National Commission: Balancing of Moral Principles in Clinical Research" in *The Ethics of Research Involving Human Subjects: Facing the 21st Century*, Vanderpool (ed) Frederick Press: 83.

⁸ Laine and Davidoff, "Patient-Centered Medicine: A Professional Evolution" 275 *JAMA* 152 (1996): "Beyond 'honesty is the best policy', the argument for informing patients is that information enables patients to participate in medical decisions. In more physician-centered days, physicians would decide what was best for their patients, and patient participation was limited to compliance with the physicians' orders. As medicine becomes more patient centered, participation begins with the patient helping to decide what the physician will order, and he emphasis shifts from compliance to participation."

⁹ Bayer and Fairchild, above at n 6 at pp.193-194. Here, the commentators document "the intense concern of gay men about threats to privacy and civil liberties" which led to, what was seen as a necessary, "voluntarist" approach.

political assertion¹⁰ after the Stonewall resistance in the New York City summer of 1969.

12. My life was lived in the tail-end of this phenomenon. After a failed marriage, and thirty years in the closet, I came out as an unapologetically gay man at the end of 1982. My own period of elated personal expression and sexual freedom was intense but short-lived.
13. The AIDS epidemic fell upon us with inexpressible horror. The disease was mysterious, horrific in the slow fleshly decline it exacted, and inexorably deadly.
14. The response to those succumbing to it was not just fear, but rage. There could be no such abrupt and ghastly end to the idyll of gay freedom. There had to be a means of restoring it.
15. To the extent that doctors, scientists and government officials stood in the way of treatment or a cure, their title to do so was subjected to enraged challenge.¹¹
16. It was no longer enough for doctors to tell patients dying of AIDS what to do. The management of the disease had to be a partnership in which the sick and dying men (for it was, at first, mostly men) and their circle of family and friends participated.

¹⁰ Carter, *Stonewall: The Riots that Sparked the Gay Revolution*, St Martin's Press (2004).

¹¹ Mann, Gostin, Gruskin, Brennan, Lazzarini and Fineberg, "Health and Human Rights" *Health and Human Rights* 1994, 1:16. Here, Mann et al categorically state that "it may be useful to adopt the maxim that health policies and programs should be considered discriminatory and burdensome on human rights until proven otherwise." See also Bayer and Fairchild, "The Limits of Privacy: Surveillance and the Control of Disease" *Health Care Analysis* 2002; 10: 19-35.

17. Research protocols and processes that delayed access to possible alleviation of the disease had to be impatiently shredded.
18. And this battle was being fought while gay men like myself – mostly urbanised, mostly white, mostly professional and mostly relatively affluent – were dying in fearsome numbers.
19. By March 1985, the death toll from AIDS in the United States had reached over 4 300, and was rapidly growing.¹²
20. It was at this point that I became infected with HIV. It was Easter 1985 and already the epidemic had perceptibly brushed South Africa. The necessities of safe sex were known. And yet, in blind hope and carnal urgency, I breached them. That act of vulnerability changed my life, and nearly took it. It is unceasingly humbling reminder when I talk to audiences about prevention and life-saving choices.
21. Fired by the angry rage of dying activists, patient treatment protocols, research procedures and drug availability processes were revolutionised.¹³
22. The resulting benefits were not confined to AIDS. Nor were they limited to middle class men in North America and Western Europe. And their impact stretched far beyond the 1980s.
23. A world-wide activist movement has meant that Africans, urbanised, working class and rural, are as assertive, as informed and as clamant for

¹² Shilts, *And the Band Played On: Politics, People and the AIDS Epidemic*, St Martin's Press (2007); *Los Angeles Times* March 22, 1985, available at http://articles.latimes.com/1985-03-22/news/mn-29763_1_death-toll (accessed 15 October 2012).

¹³ Hoffmann, "Health Care Reform and Social Movements in the United States", *Am J Public Health*, January 2003; 93(1): 75-85.

proper care and access to treatment as the gay Westerners who were first identified with AIDS.¹⁴

24. This shift took place as part of a more general evolution in attitudes to authority in the western world and Africa. Political representatives, national leaders, religious figures and professionals of all disciplines, including judges, were either knocked from their perches or had their perches significantly lowered.
25. Reverence and respect were replaced by questioning and doubt.¹⁵ Reliance could no longer be claimed, but had to be earned.
26. This we can characterise quite generally as a shift from *trust* and *reliance* to *scepticism* and *doubt* about institutional and professional decision-making for others.
27. This shift is also evident in the other two ways in which AIDS has changed our world.

Intellectual Property and the Morality of Death

28. The second way concerns the morality of death. At about the very time it became known in the mid-1990s that AIDS could be effectively managed through a sustained programme of antiretroviral treatment, the impact of AIDS on the continent of Africa was taking its fiercest toll.¹⁶

¹⁴ Grebe, "Transnational Networks of influence in South African AIDS treatment activism", *Working Paper No.5*, Centre for Social Science Research, AIDS and Society Research Unit (aids2301).

¹⁵ Brazier and Lobjoit, "AIDS, ethics, and the respiratory physician", Centre for Social Ethics and Policy at pp.283-286.

¹⁶ Bayer and Fairchild, "The Genesis of Public Health Ethics", in *Bioethics Reader, Editors' Choice*. Chadwick, Kuhse, Landman, Schuklenk and Singer (eds) Blackwell Publishing Ltd (2007) at p.196.

29. To be sure, Ugandans had died in large numbers in the 1980s.¹⁷ But so had white gay men in the affluent societies of the global North.
30. By the mid-1990s, the global burden of disease in the epidemic was overwhelmingly black, heterosexual and African. By a ghastly converseness, just as death from AIDS in affluent societies began to be defeated, the body count in Africa, and particularly in my country, South Africa, started to rise.¹⁸
31. What then happened was most remarkable, and completely unprecedented.
32. Though the global epidemic was vividly distinguished by race, orientation, geography and material conditions of living, a bridge was formed across these divides to wage a common fight against unnecessary and unwarrantable death.
33. That fight has revolutionised our conception of intellectual property and death.¹⁹
34. The demographic shift from *white affluent male and mostly gay*, to *poor black heterosexual and preponderantly female* was most evident in my country.

¹⁷ Monica, Tanga, Nuwagaba, Aggleton and Tyrer, "Uganda: HIV and AIDS-related Discrimination, Stigmatization and Denial", *UNAIDS* (August 2001) at p.6.

¹⁸ Id; see also Whitesale "Demography and Economics of HIV/AIDS" *British Medical Bulletin* (2001) 58(1): 73-88 (available at: <http://bmb.oxfordjournals.org/content/58/1/73.full>).

¹⁹ Hoen et al "Driving a Decade of Change: HIV/AIDS, Patents and Access to Medicines for all", *Journal of International AIDS Society* 2011, 14: 15.

35. When negotiations to end apartheid started in 1990, the national prevalence was less than 2% (1.7%)²⁰. In 1994, when we became a democracy, it was nearly 8% (7.6%).²¹ By the turn of the last century, the prevalence was 22.4% – and annual AIDS deaths were well over 350 000 (381,820).²²
36. In late 1998, a dynamic activist, himself living with HIV, started the Treatment Action Campaign in South Africa. He was Zackie Achmat. The TAC was formed to tackle drug-pricing.²³ It did so through a frontal assault on the very edifice of moral claims by which drug manufacturers and distributors sought to justify the prices they charged. The war on prices entailed a war on the mostly-unexamined assumptions of intellectual property law itself.
37. Rightly, the activists personalised the issues. The faces of drug company executives and board members were brandished on placards at angry public demonstrations. The bonuses paid to drug company executives – sometimes running into tens and even hundreds of millions of dollars – were contrasted with the searing poverty in which those they denied access to life-saving treatment were dying.²⁴
38. In the end, the contrast became politically and morally unsustainable.
39. A pivotal moral proposition was propounded and asserted, and became established. It was that it was intolerable for Western governments and

²⁰ <http://www.avert.org/south-africa-hiv-aids-statistics.htm>. See also Cameron, “What you can do with rights” at The Fourth Leslie Scarman Lecture (2012), Law Commission of England and Wales at [42]-[44].

²¹ *Id.*

²² *Id.*

²³ Nattrass, *Mortal Combat: AIDS denialism and the struggle for antiretrovirals in South Africa* (2007).

²⁴ *Id.*

the corporations whose activities they licensed to permit tens of millions of poor Africans to die, while treatment that would save their suffering and restore them to life and health was cheaply available.

40. By 2003, with the help of the Gates and Clinton Foundations, the battle of drug pricing had been won.²⁵
41. It was a signal victory for principled activism and for civil society organisation.
42. But it was only part of a larger war. That war continues. As Achmat has said –

“The treatment access movement in Africa mobilised the first successful post-independence continental citizen’s movement based on openness about HIV. This transformed HIV from a discussion about sex and death to a [broader] discussion about sex, health and the right to life.”²⁶
43. The activists’ claim to life entailed re-examination of research focus, product output and treatment access. The hoary claims about research and development costs were subjected to passionately sceptical scrutiny.
44. A new world system for the reward of innovation and the distribution of available treatment is being forged.²⁷

²⁵ *Minister of Health and Others v Treatment Action Campaign and Others* (No 2) [2002] ZACC 15; 2002 (5) SA 72 (CC) (5 July 2002). See also Heywood “South Africa’s Treatment Action Campaign: Combining Law and Social Mobilization to Realize the Right to Health”, *Journal of Human Rights Practice* (2009) 1(1) 14-36.

²⁶ Private email communication of 2 October 2012.

²⁷ Pogge. “Human Rights and Global Health: A Research Program” *METAPHILOSOPHY* Vol 36, Nos ½ (Jan 2005) available at <http://ducis.jhfc.duke.edu/wp-content/uploads/2010/06/Pogge-Human-Rights-and-Global-Health-1.pdf>

45. It may yet be a long time coming. There are enormous conceptual and institutional complexities, as well as deeply powerful vested interests, that militate against reform.
46. Nevertheless, there is a perceptible movement towards the evolution of principles of global distributive justice in health care beyond AIDS and even beyond health care.
47. All this has been triggered by death from AIDS.²⁸
48. The debate about AIDS deaths in Africa changed our conception not only of whether poor people should be allowed to die needlessly, when treatment for their condition is available, but on the system of enforceable rights and entitlements that would, if applied, without more, have left them to die.
49. Death induced by determination to maintain the rigidities of drug pricing and of proprietary entitlements became noxiously unacceptable.

Stigma, Self, Autonomy and Choice

50. A third way in which AIDS has changed our world forms the core of my talk tonight.

²⁸ Niekerk and Kopelman “Principles of global distributive justice and the HIV/AIDS pandemic: moving beyond Rawls and Buchanan”, in *Ethics & AIDS in Africa: The Challenge to our Thinking*, David Philip Publishers (2005), Chapter 6 at p.87. Building on Rawls’ theory of distributive justice to a notion of “fair equality of opportunity” it is argued that equal distribution ought to be the result of a social contract to which all that are affected by its contents should contribute in equal measure. In *Just Health Care* (CUP 1985) Daniels theorises the “fair equality” principle into four levels of practical aspiration, namely: i) preventative health-care that minimizes the likelihood of departures from the “normality assumption”; ii) institutions that deliver personal medical and rehabilitative services that restore normal functioning; iii) institutions that offer more extended medical and social support services for people who are (moderately) chronically ill or disabled, including the frail and elderly; and iv) institutions that take care of people who are seriously ill in the sense that they cannot be brought closer to the idealization mentioned in (iii).

51. The first two ways, the relation of subject to science, and the application science to death [or in the preservation of life], were triggered by, and in their turn hastened, a shift from trust, reliance and authority to scepticism, doubt and mistrust.
52. The third impact of the epidemic is as yet only partially understood, and very sparingly explored. Its impact is on the notions of self, autonomy and choice²⁹ – and they have only begun to be explored.
53. Unsettlingly, this third lesson from AIDS suggests the need for a counter-shift – in other words, for a re-assertion of reliance, authority and trust.³⁰
How is this?
54. There is no question as to what has been the most signal feature of the public response to AIDS, and of the political management of the disease: it has been stigma.³¹
55. Perhaps AIDS can be called the most stigmatised disease in human history. While other horrific lethal ailments, like the Black Death, tuberculosis and leprosy, were stigmatised for well-warranted reasons of contagion, AIDS is stigmatised even though it is not contagious, and even though its infectious agent is extremely hard to transmit.

²⁹ Crisp, “Autonomy, Welfare and the Treatment of AIDS”, *Journal of Medical Ethics*, 1989, 15, 68-73. For other discussions see Veatch, “Abandoning Informed Consent”, *Hastings Center Report* 25:2 (March/April 1995), p.642; and De Cock, “Shadow on the Continent: public health and HIV/AIDS in Africa in the 21st Century” (The Economics of HIV in Africa), *The Lancet* Vol 360 Issue 9326, 6th July 2002 p1.

³⁰ Bayer and Fairchild “Changing the Paradigm for HIV Testing – The End of Exceptionalism” *New England Journal of Medicine* 355; 7 (August 17, 2006).

³¹ Parker & Aggleton, “A conceptual framework and basis for action: HIV/AIDS stigma and discrimination”, *UNAIDS, World AIDS Campaign, 2002-203* at p.8: “Within a particular culture or setting, certain attributes are seized upon and defined by others as discreditable or unworthy. Stigmatization therefore describes a *process of devaluation rather than a thing.*”

56. Indeed, in 95% of cases its transmission occurs through a narrow vector – unprotected, ejaculative, vaginal or anal intercourse.
57. And in this lies the key to stigma – namely sexual transmission. The puzzles surrounding AIDS stigma are especially deep, but that they relate to sex seems to me unquestionable.
58. A moment of intensely private, shared bodily union, which should be effusive, joyful, gratifying, exultant, and, in the case of an opposite-sex couple, potentially generative, becomes instead a moment in which an infectious agent is passed: in the case of HIV, a lethal agent.
59. In this there is something deeply mortifying, distressful and ultimately shameful.
60. From embarrassment and shame spring condemnation, and from condemnation springs ostracism and discrimination.
61. The external manifestations of stigma in the AIDS epidemic are well understood and have been exhaustively described.³²
62. What is less well understood, and has indeed been infrequently described, is its internal dimension.

³² Greeff et al, “Experiences of HIV/AIDS Stigma of Persons Living with HIV/AIDS and Nurses Involved in their Care from Five African Countries”, *Afr J Nurs Midwifery*, 2008; 10(1): 78-108 see pp.79-81 and the itemization of: (i) internal stigma, (ii) received stigma and (iii) associated stigma. See also Mahajan et al, “Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward”, *AIDS*. 2008 August; 22 (Suppl 2): S67 – S79 at p.5, citing Link and Phelan: “stigma exists when the following four interrelated components converge: 1) individuals distinguish and label human differences, 2) dominant cultural beliefs link labelled persons to undesirable characteristics (or negative stereotypes), 3) labelled persons are placed in distinct categories to accomplish some degree of separation of “us” from “them” , and 4) labelled persons experience status loss and discrimination that lead to unequal outcomes.”

63. For the most powerful operation of stigma is not in its enacted form, namely in discrimination and social rejection, but in its internalised form.
64. The internalisation of stigma has been relatively little studied, relatively seldom described and, when undertaken, all too often misdescribed.³³
65. Internalised stigma is wrongly confused with “felt”, “apprehended” or “perceived” stigma.³⁴
66. It is none of these. It is a deeply internal state of shame, fear and self-blame that arises from feelings of contamination, pollution and defilement with a virus that through sexually transmission has become lodged in the body.
67. This I experienced all too vividly and all too personally. When I received my diagnosis with HIV in 1986, I was a young man in my early 30s. I had a vigorous human rights practice at a trying but exhilarating time in my country’s history. My diagnosis meant certain death. Before I turned 40,

³³ For example, in Roura et al, “Just like fever: a qualitative study on the impact of antiretroviral provision on the normalisation of HIV in rural Tanzania and its implications for prevention”, *BMC International Health and Human Rights*, 9th September 2009 it is stated that: “Malcolm, Aggleton and Bronfman (1998) stated that perceived or “felt” stigma often *precedes* rather than results from the experience of stigma. They claim that many individuals reduce the opportunity for “enacted” stigma in order to protect themselves from discriminatory actions”. This must be wrong. There can be no internalization of a non-existent phenomenon. The source of internal stigma must be external discrimination and prejudice, though this is later appropriated and directed inwards. To say that one feels anticipated stigma looks a bit like blaming the victim. And, one might ask – “anticipation of what?” The answer must be external prejudice. Therefore, while an individual may fall into internal turmoil before being the direct subject of a comment or injurious remark, this is not the same as saying that felt stigma precedes external stigma. One cannot deny the source of internal stigma is the external prejudices expounded and manipulated by a society.

³⁴ Greef et al; Hasan; Sengupta; MacPherson; see also Parker & Aggleton (May 2002), who refer to internalized stigma as “fear of HIV/AIDS-related stigma and discrimination”. Mahajan et al, “Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward”, *AIDS*, 2008 August; 22 (Suppl 2): S67 – S79 refer to internalised stigma only once, and in passing, saying “Public participation of PLHA [people living with HIV and AIDS] at community and social levels would not only promote individual level responses to internalized stigma on the part of PLHA, but could also prove a powerful deterrent to stigmatizing impulses of the general population”.

before South Africa was liberated, before I could realise any of my personal or professional ambitions, I would be dead from AIDS.

68. But worse, far worse, worse even than my calamitously foreshortened expectation of life, was the shame I felt.
69. It was intense, all-encompassing and overpowering. It disabled me from talking to my closest friends and my beloved family. It forced my retreat into a frozen wasteland of isolation for three years. It precluded even contemplating help from others, still less calling for or accepting it. It transcended and overpowered the capacity for rational thought.
70. Feelings of shame about illness are not novel. All fatal disease, perhaps all disease, induces embarrassment and shame.
71. In his just-published novel, *Sweet Tooth*, set in the early 1970s, British author Ian McEwan creates a character who slinks away to die of cancer, without telling those most intensely involved in his life. The narrator – also kept out of the secret – muses:

“Cancer was a disgrace, the victim’s, that is, a form of failure, a smear and a dirty defect, of personality rather than flesh.”³⁵
72. What is different with HIV, and what makes the disgrace and failure, the dirt and defect, immeasurably more intense, is the fact that it is sexually transmitted.
73. Indeed, given the intensity of the phenomenon, its non-description, or mis-description, in the literature of AIDS is genuinely puzzling.

³⁵ McEwan, *Sweet Tooth*, Nan A Talese (2012).

74. And it is the more baffling because the phenomenon is well-known in other settings. The “self-hating Jew”, the “self-loathing gay” are readily recognisable constructs of the psychological and other literature.
75. In South Africa’s vile past of racial hatred, Steven Bantu Biko recognised that the stigma of racial subordination had an internal impact that had to be eradicated first, if notions of white superiority and black subordination were to be effectively overcome.³⁶
76. Indeed, the founding modern analysis of stigma, that by Erving Goffman in 1963, itself recognises that “the social label of deviance compels stigmatised individuals to view themselves...as discredited or undesirable”.³⁷
77. Yet the profound impact of internalized stigma in the AIDS epidemic has seemed resistant to proper study and understanding.³⁸

³⁶ For a vivid recent explanation of Biko’s philosophy, see Aubrey Masango, “Constructive criticism: If we can’t give it, who can?”, available at <http://dailymaverick.co.za/opinionista/2012-10-02-constructive-criticism-if-we-cant-give-it-who-can> (accessed 16 October 2012). Masango says that Biko understood that “the true emancipation of a deeply oppressed people would not simply come as a result of political emancipation alone”. Hence, his idea was that freedom comes first in “freedom from our destructive selves”. Freedom exists – “in the mind first – that until such deep-seated slavery was appropriately understood and uprooted through appropriately contextualised knowledge of oneself and one’s history, political emancipation would only facilitate the entrenchment of mental slavery. Worse still, it would perpetuate it through black Neo-colonialism. This is why Biko said ‘the most powerful weapon in the hands of the oppressor...is the mind of the oppressed’.”

³⁷ Goffman, *Stigma: Notes on the Management of Spoiled Identity*, Penguin Books, 1963, page ***. Goffman comes tantalizingly close to identifying the power of internalized stigma but never quite does. Thus, he notes of the stigmatized person that “the standards he has incorporated from the wider society equip him to be intimatedly alive to what others see him as his failing, inevitably causing him, if only for moments, to agree that he does indeed fall short of what he really ought to be. Shame becomes a central possibility, arising from the individual’s perception of one of his own attributes as being a defiling thing to possess, and one he can readily see himself as not possessing” (page 18). “If only for moments” falls short of appreciating the long-term embedded force of internalized stigma, particularly in the setting of disease. Graham Scambler, “Health-related stigma”, *Sociology of Health and Illness* vol 31 no 3 2009 pages 441-455, provides an insightful overview of Goffman’s impact.

³⁸ The most lucid analysis I have come across is Brouard and Wills, “A closer look: the internalisation of stigma related to HIV”, Washington DC: *US Agency for International Development*; 2006, p.1.

78. Why? We may posit a number of reasons.
79. First, internalised stigma is imperceptible. It an internal phenomenon and deeply elusive. It is hard to detect and discern. Its operation consists in self-disablement, and therefore in inaction or omission (avoidance of testing, care, treatment).
80. A second reason is that confronting internalised stigma runs the perilous risk of seeming to blame the victim. With external stigma we have a perpetrator and we have a victim. The villain is easy to see. It is easy to condemn the condemner, the discriminator, the excluder.
81. By contrast, with internalized stigma, we have no perpetrator. There is only a victim. And the search for a perpetrator seems, unsettlingly, to lead to blaming the victim.³⁹ Indeed, one of misleading terms used in the sparse literature on the subject is “self-stigma.”⁴⁰ The imputation of agency, action, responsibility and therefore blame is erroneous, but quite inexorable.
82. Yet this replicates the very experience of self-condemnation, self-disentitlement and self-disablement that are the operational effects of internalised stigma.
83. A third reason we shy away from it is this: What to do? Even if we better understood internalised stigma, how would we go about combating

³⁹ Hasan et al “Internalized HIV/AIDS-related Stigma in a Sample of HIV-positive People in Bangladesh”, *Journal of Health, Population and Nutrition*. 2012 March; 30(1): 22-30.

⁴⁰ Corrigan, “Self-Stigma and the “why try” effect: impact on life goals and evidence-based practices”, *World Psychiatry* June 2009; 8(2): 75-81. Steward et al, “HIV-related stigma: adapting a theoretical framework for use in India” *Social Science and Medicine* 2008, 67, 8, 1225-1235, also use “self-stigma”, though they provide a helpful distinction between “felt normative stigma” and internalized stigma.

it? It is so intractably difficult to address that it seems to defy practical programmatic practical response. Indeed, to say to the subject “you feel ashamed”, “you feel isolated” may only give external definition to a tacit internal turmoil, without providing the remedy. Hence we run away from it.

84. Yet practically it continues to operate with profound power. Internalised stigma causes those –

- who fear testing positive to avoid being tested even when they know that treatment is available;
- with HIV to avoid seeking treatment, even when they know that treatment will restore them to health;
- who are experiencing the dread, debilitating effects of bodily decline to mask their suffering from loved ones and colleagues, even when objective assurance exists that, if they tell, they will receive only love and support.⁴¹

85. Internalised stigma causes suffering and death. In my country, it still does on a massive scale.

86. Stigma is abating. But only slowly, and only slightly.

87. Because of the success of the treatment activists, South Africa today has the world’s largest publicly provided treatment action programme. I have been on ARV treatment since November 1997 – nearly 15 years. The last time any instrument of medicine or science was able to detect the virus itself in my body (as opposed to its antibodies) was 12 years ago.

⁴¹Hasan et al “Internalized HIV/AIDS-related Stigma in a Sample of HIV-positive People in Bangladesh”, *Journal of Health, Population and Nutrition*. 2012 March; 30(1): 22-30.

88. The good news is that my good fortune is shared by over 1.7 million South Africans.
89. The near-miraculous properties of ARV treatment are everywhere on display. They enable a full and vigorous life and now appear to confer longevity, at least according to recent Danish studies,⁴² in comparable measure to persons living without HIV. This has caused stigma to abate.
90. Sadly, the fact that we are now in what epidemiologists call, with poignant understatement, a “mature epidemic”⁴³ – one in which every South African, black or white, in suburb or township, town or country, knows someone who has died of AIDS – has also helped lessen the effects of stigma.
91. Yet, intractably, and with debilitating force, the effects of internalised stigma continue.
92. Last year, more than 200,000 people in South Africa died of AIDS.⁴⁴ Some of these deaths are due to poor medical outreach, to treatment

⁴² Obel et al “Impact of non-HIV and HIV risk factors on survival in HIV-infected patients on HAART: a population-based nationwide cohort study”, PLoS One. 2011;6(7):e22698. Epub 2011 Jul 25, abstract available at <http://www.ncbi.nlm.nih.gov/pubmed/21799935> (accessed 16 October 2012), conclude that “Mortality in patients without risk factors on a successful HAART is almost identical to that of the non-HIV-infected population”; while Helleberg et al “Causes of death among Danish HIV patients compared with population controls in the period 1995-2008”, Infection. 2012 Jul 12. [Epub ahead of print], abstract available at <http://www.ncbi.nlm.nih.gov/pubmed/22791407> (accessed 16 October 2012) conclude that “After the introduction of highly active antiretroviral therapy (HAART), the AIDS-related mortality has decreased substantially, but the long-term exposure to HIV and HAART has not translated into increasing mortality from malignancy, cardiovascular, and hepatic diseases”.

⁴³ Hearst and Mandel, “A Research Agenda for AIDS Prevention in the Developing World”, AIDS, 1997 Sep; 11 Suppl 1: S1-4

⁴⁴ Mid-year Population Estimates 2010, *Statistics of South Africa*, Statistical Release PO302 released 20th July 2010. See also www.unaids.org/en/regionscountries/countries/southafrica; www.tac.org.za/community/keystatistics.

unavailability and to late starts on treatment. A very few may be due to treatment failure.

93. But, overwhelmingly, the cause of continuingly high AIDS deaths is internal. It is the self-disabling fear of diagnosis that keeps people in their hundreds of thousands from accessing treatment and from being restored to health.
94. Let me recount two vivid anecdotes.
95. A South African cabinet minister died earlier this year. His death was repeatedly described as due to “a long illness”. A leading newspaper wrote a moving reflection on this “long illness”,⁴⁵ wondering why the disease that probably took the life of the political leader and so many other public figures was not named. The newspaper was taken to task by a well-known commentator for “insinuating” that the politician died of AIDS.⁴⁶
96. Then an attorney friend of mine with recent family roots in the rural areas of Kwazulu-Natal, where our national prevalence is highest, lost a sister to AIDS last year. Rather than accept her well-resourced, professional brother’s offer to fund her medical care, she returned to her village, alone and untreated to die in solitude.

⁴⁵ “He died of ‘a long illness’”, *City Press* Sunday 6 May 2012, available at <http://www.citypress.co.za/Opinions/Editorials/He-died-of-a-long-illness-20120505> (accessed 16 October 2012).

⁴⁶See Eusebius McKaiser, “Media ethics in a time of fear and stigma”, *Mail & Guardian* 10 May 2012, available at <http://mg.co.za/article/2012-05-10-media-ethics-in-a-time-of-fear-and-stigma> (accessed 16 October 2012). The criticism seems wrong. One only “insinuates” a condition or conduct that is held despicable.

97. When I publicly announced in April 1999 that I was living with HIV and that my life had been saved by access to treatment, I thought it would be a matter of only very little time before others – public figures, politicians, soccer players, entertainers, cabinet ministers and judges – joined me. It has not happened. I remain the only the person holding public office on the entire continent of Africa who has spoken publicly about living with HIV.
98. The cause is not fear of any adverse external effects, for the response to a public announcement would, as I experienced, be lavish praise and loving affirmation. The cause is the immobilising effects that spring from the internalisation of stigma.
99. What does this feature of the epidemic mean for our world beyond AIDS? It has a profound effect. It challenges notions of volition, self and autonomy in ways that are intensely pertinent to the management of AIDS, but ripple also far beyond it.⁴⁷
100. The effects of internalised stigma have all but been ignored in the debate that has taken place over the last 15 years about the management of the epidemic and the treatment of those living with, and at risk of, HIV.
101. This has included debates about –

⁴⁷ For some of the commentary see Macklin “The Doctor-Patient Relationship in Different Cultures” in *Against Relativism: Cultural Diversity and the Search for Ethical Universals in Medicine* Oxford University Press, 1999 and compare Bayer and Fairchild “The Genesis of Public Health Ethics” in *Bioethics Reader, Editors’ Choice*, Chadwick, Kuhse, Landman, Schuklenk and Singer (eds), Blackwell Publishing Ltd (2007), Chapter 12 at p.207. Indeed here a ringing endorsement is given to a robust embrace of a paternalistic model in that interventions ought not to be justified merely on a moralistic harm principle but on the basis that “we are morally bound to prevent avoidable suffering and death.”

- the necessity for counselling, before and after an HIV test;⁴⁸
- the form in which consent should be sought for testing;⁴⁹
- the places where and population in which testing should occur;⁵⁰
- the form in which the medical apparatus with which to test should be made available;⁵¹
- the level of confidentiality that should attach to a diagnosis of HIV;⁵² and
- the question whether mass testing to expand treatment so as to diminish the incidence of HIV should be contemplated.⁵³

102. Professor Bayer⁵⁴ says that “on the most fundamental level...the struggle that crystallised around HIV testing asked whether a human rights perspective informed by an exacting conception of individual rights should prevail over one in which the claims of public health could legitimately impose limits on consent.”⁵⁵

103. This correctly frames the issue. And I have been on Professor Bayer’s side of it.

104. But what it obscures in its unexamined reference to “consent” is the *nature* of the consent that is sought, and the subject’s capacity to give it.

⁴⁸ Wachbroit and Wasserman “Patient Autonomy and Value-Neutrality in Nondirective Genetic Counselling” *Stanford Law and Policy Review* 6:2 (1995) at pp.103-11.

⁴⁹ Veatch, “Abandoning Informed Consent” *Hastings Center Report* 25:2 (March/April 1995), pp.636-645.

⁵⁰ De Cock “Shadow on the continent: public health and HIV/AIDS in Africa in the 21st Century”, *The Lancet* Vol 360 Issue 9326, 6th July 2002 p.1.

⁵¹ De Cock and Johnson “From exceptionalism to normalisation: a reappraisal of attitudes and practice around HIV testing”, *British Medical Journal* Vol 316 24 January 1998.

⁵² Bayer and Edington “HIV Testing, Human Rights, and Global AIDS Policy: Exceptionalism and Its Discontents”, *J Health Policy Law* 2009 June; 34(3): 301-323.

⁵³ Burci and Koskenmake, “Human Rights Implication of Governance Responses to Public Health Emergencies: The Case of Major Infectious Disease Outbreaks”, in *Multilateral Institutions and Responses*, p.346-358.

⁵⁴ And his co-author Professor Edington.

⁵⁵ Bayer and Edington, “HIV Testing, Human Rights, and Global AIDS Policy: Exceptionalism and Its Discontents”, *J Health Polit Policy Law* 2009 June; 34(3): 301-323.

105. Professor Bayer rightly describes the risk that the exceptionalist approach to AIDS, reinforced by a rigid insistence on human rights protections, “contributed to the stigma”.⁵⁶
106. But what is lacking is the appreciation of the pivotal, disabling and immobilising role that internalised stigma has played in this.⁵⁷
107. What is critical here is not that this insistence on misplaced human rights protections enhanced stigma – for it plainly did – but that it reinforced internalised stigma, in particular, and in effect, deprived those experiencing it of a real opportunity to choose.⁵⁸
108. Internalised stigma is so powerful that it necessitates some reflective re–assessment of the notion of autonomy itself.
109. It is trite that autonomy represents the capacity to govern the self and to make independent choices.⁵⁹

⁵⁶ Bayer and Edington, above.

⁵⁷ Likewise, De Cock and others “Shadow on the Continent: public health and HIV/AIDS in Africa in the 21st Century” (The Economics of HIV in Africa), *The Lancet* Vol 360 Issue 9326, 6th July 2002 p.1 comes from a different perspective. He contends that the normalization of HIV clinical practice and enhancing access to testing is a crucial first step toward realizing the rights of “uninfected people to remain HIV negative, or infected individuals to benefit from treatment and prevent advice and of society to reduce the effects of HIV/AIDS.” I don’t make the contrast with “uninfected people”, and Dr De Cock doesn’t deal with internalised stigma. De Cock was prescient in making the argument that over-wrought insistence on human rights protections damaged the interests of those with and at risk of HIV.

⁵⁸ Goffmann, “Stigma: Notes on the Management of Spoiled Identity”, *Penguin Books*, 1963. Here, Goffmann recognizes that “the social label of deviance compels stigmatised individuals *to view themselves*...as discredited or undesirable.” Indeed, it is this discredited notion of self which disables a truly autonomous decision [emphasis added].

⁵⁹ Savulescu, “Rational desires and the Limitation of Life-Sustaining Treatment”, *Bioethics* 8:3 (1994) Blackwell Publishing Ltd at pp.191-222. Here, Savulescu recognises the origins of the word “autonomy” as deriving from the Greek “autos” (self) and “nomos” (rule or law). Autonomy is, therefore, self-government or self-determination. Autonomous choice fundamentally involves evaluation. It is not mere desire, but the weighing and evaluation of alternatives by a person and the selection of that alternative which best suits that person’s judgment for how she wants her life to go.

110. Much of the literature on autonomy and consent recognises, as it must, that autonomy is a constrained concept.⁶⁰ Indeed, from a Marxian perspective, political consciousness and the capacity for autonomous choices are themselves not merely defined, but determined by material and social circumstance.⁶¹
111. There is, indeed, no “Archimedean” point⁶² – no point at which the self exists independently of the social, psychological and material forces that influence and perhaps determine it.⁶³
112. But the significance of the internalisation of stigma goes further than this. To understand internalised stigma is not merely to note the material constraints on human capacity or the social limitations of freedom. It is to assert that the psychology of disease can have such a powerfully, internalised effect as to appreciably inhibit the subject’s capacity to make rational choices.
113. It is for this reason that I supported the pleas by Professor Bayer and some of his allies⁶⁴ to de-exceptionalise AIDS. My support was context-defined, since I accept that there are discrete epidemics in which highly

⁶⁰ Indeed, Veatch at n 49 above calls autonomy a “transition concept” and Savulescu (n. 59) refers to it as being “dispositional”.

⁶¹ Macklin, “The Doctor-Patient Relationship in Different Cultures” in *Against Relativism: Cultural Diversity and the Search for Ethical Universals in Medicine*, Oxford University Press, 1999 pp.86-107. Such notions of societal-factor autonomy leads Veatch (above at n 49) to argue that a possible way of ensuring a better guess at a best interests option would be through “value-pairings” between clinician and patient. He states that “there might be more hope if the patient were to choose her cadre of well-being experts on the basis of ‘dep’ value systems... To the extent that the provider and patient were of the same mind set, then there is some reason that the technically competent clinician could guess fairly well what would serve the patient’s interest”.

⁶² See Steven Lukes, “No Archimedean Point” (a review of Rawls’s *Theory of Justice*), chapter 10 of S Lukes, *Essays in Social Theory* (1977).

⁶³ Hussein, “When Ethics Survive People Do not”, *Public Health Ethics* Vol 3 No 1 2010 p.72-77.

⁶⁴ Bayer and Edington “HIV Testing, Human Rights and Global AIDS Policy: Exceptionalism and Its Discontents” *J Health Polit Policy Law* 2009 June; 34(3) 201-323. See also, Dubler, Levin “Building a new consensus: Ethical Principles and policies for clinical research on HIC/AIDS” *IRB* 1991 13:1-24; De Cock “Shadow on the continent: public health and HIV/AIDS in Africa in the 21st century”, *The Lancet* Vol 360, Issue 9326, 6 July 2002 p.1.

vulnerable groups are mainly at risk, and may be victimised by uncaring health care providers.

114. But once treatment has become available in a mass epidemic, “normalisation” means that AIDS should be as far as possible as just another disease.⁶⁵
115. In these conditions, the palaver and hubbub attending human rights protections, designed to protect those with and at risk of HIV, instead become their enemy, not just because they make it objectively more difficult for them to access testing and treatment – but because they reinforce the internalised power of stigma.⁶⁶
116. Human rights advocates, including my own close comrades, who have sought to protect those with, and at risk, of HIV, have all too often failed to understand the devastating incapacity internalised stigma inflicts on those who experience it.
117. They have on occasion accused those who seek to enable easier access to testing of showing “paternalism”, when it is surely they who are manifesting it – for in foisting on those immobilised by internalised stigma a conception of the voluntary self that is inapposite to their capacities, they omit to create a properly enabling environment for the true exercise of choice.⁶⁷

⁶⁵ Roura et al “Just Like Fever”, *BMC International Health and Human Rights* 2009, 9:22.

⁶⁶ Nixon and Forman, “Exploring synergies between human rights and public health ethics: A whole greater than the sum of its parts”, *BMC International Health and Human Rights*, 2008; 8:2.

⁶⁷ Savulescu,, “Rational desires and the Limitation of Life-Sustaining Treatment”, *Bioethics* 8:3 (1994), Blackwell Publishing Ltd at p.647. By way of analogy with the story of Ulysses and the Sirens, Savulescu makes a case for severe observance of only those choices which externalise expression of rational desires i.e. the autonomous, rational desire to remain chained to the ship rather than the irrational and obstructive desire to answer the seductive song of the Sirens.

118. As one bioethicist has perceptively noted in the context of depression and the “choice” to commit suicide, “one cannot logically be self-determining if one believes that the path one sets upon is the only path available.”⁶⁸
119. The phenomenon of internalised stigma is the big un- or at least under-spoken issue in the AIDS epidemic – and yet it may be one of the most significant lessons the epidemic has for bioethics, public health and principles of human rights.
120. Its significance is this. First, human rights protections run the risk of reinforcing internal isolation and limiting choice. This, after treatment has become available in mass epidemics, has all too often been the effect of insistence on human rights observances.⁶⁹
121. Second, the shift over the last 60 years, and particularly over the last 30 from trust, reliance and authority to scepticism, doubt and mistrust has created both benefits and burdens.
122. Scepticism and mistrust have unmasked falsehood in public life, condescending intrusion on people’s lives, and the imposition of inappropriate value-systems through power.⁷⁰

⁶⁸ Id. Savulescu argues that being self-determining entails that a particular evaluation or decision must involve three elements, and they are: i) knowledge of relevant, available information concerning each of the potential states of affairs, ii) no relevant, correctable errors of logic in evaluating that information, and iii) vivid imagination by the person of what each potential state of affairs be like for them. Those desires which satisfy each of the prerequisites can be termed “rational desires”.

⁶⁹ Gruskin, “Ethics, Human Rights and Public Health” *American Journal of Public Health*, May 2002, Vol 92, No. 5. See also Gruskin and Tarantola “Health and Human Rights” in Detels, McEwan, Beaghole and Tanaka (eds), *The Oxford Textbook of Public Health* 4th ed (Oxford University Press).

⁷⁰ Parfit, *Reasons and Persons* (Oxford: Clarendon Press, 1984) pp.493-503. Derek Parfit considers that there are three major groups of answers to the question of “what does it mean to say that something is in a patient’s best interest. Hedonistic Theories posit that what best serves someone’s interest is that which makes the person’s life happiest. Desire-Fulfilment Theories suggest that what would be best for someone is what, throughout his life, would best fulfil his desires. Finally, Objective-List Theories state that certain things are good or bad for us, whether or not we want to have the good things, or to avoid the bad.

123. But they have also created burdens.
124. An inappropriately over-individualised – or indeed romanticised – conception of personhood does both physician and patient, public health practitioner and population, a disservice. It does the professional a disservice by assuming that his or her recommendations or choices for the patient or the population will too often be wrong.⁷¹
125. It does the patient and the population a disservice by depriving them of the benefit of beneficent and expert guidance.
126. The blunt truth is that human life is frail, that survival is contingent and that choices are precarious. We cannot avoid the need for love, friendship, support and assistance.
127. The experience of internalised stigma in the AIDS epidemic reinforces the importance, in some circumstances, of accepting our capacity and need to invoke trust and authority.
128. To tackle my dear friend and colleague Michael Kirby quite frontally, sometimes “nanny does know best”.⁷²

⁷¹ Veatch, “Abandoning Informed Consent” *Hastings Center Report* 25:2 (March/April 1995), pp.636-645 at p.642 emphasises the practical and moral complexities of obtaining genuine informed consent to medical procedures. The fundamental basis for revising the concept is that the clinician cannot be expected to know what is best for the patient, and so can never obtain a valid consent to a recommended treatment. Veatch states that “it is simply hubristic for clinicians to believe that, out of the hundreds of subtle tradeoffs to be made, they can come up with the just course that will maximise the patient’s well-being.” (p.641).

⁷² Kirby speaking at the International AIDS Society’s July 2007 meeting in Sydney, Australia. Here, Kirby states that “[t]he fundamental notion of health care ethics...demands affirmative patient consent to significant medical procedures...This is not an individual right. It is not the privilege of health care workers for the patient on the basis that ‘nanny knows best!’” quoted in Bayer and Edington “HIV Testing, Human Rights and Global AIDS Policy: Exceptionalism and Its Discontents”, *J Health Polit Policy and Law*, 2009 June; 34(3) 301-323.

129. Let me explain. Where treatment is available in a mass epidemic of HIV, it is wrong-headed, misguided, un-beneficent and adverse to positive life choices to insist on misconceived conceptions of patient “autonomy”, when the core of it has been eaten out by self-disabling horror of a positive diagnosis.
130. To expect of a patient, suffocating under the weight of internalised conceptions of contamination, pollution and vileness to make a rationally informed and wholly independent “choice” to accept HIV testing is condescending, paternalistic and misguided.⁷³
131. It is paternalistic because it intrudes on the best conditions for optimal decision-making. It is condescending because it assumes, wrongly, to know the life experience and burdens that the internally stigmatised person is carrying.
132. In some situations our human frailty and the limits of our knowledge and strength of will, and the deficiencies of our insight, require that we should be able to rely on the wisdom and beneficence of others.⁷⁴
133. This debate has much wider implications than for HIV alone. It requires us to re-examine our conception of the self, of personhood and of autonomy.

⁷³ Bayer and Edington id.

⁷⁴ See discussion of the limits of a “four-principled” approach (Autonomy, Beneficence, Maleficence and Justice) by Callahan “Principlism and Communitarianism” *Journal of Medical Ethics*, 2003; 29: 287-91 *contra* Gillon “Ethics needs principles – four can encompass the rest – and respect for autonomy should be “first among equals”, *Journal of Medical Ethics* 2003; 29: 307-312.

134. This is not an idle debate or an academic indulgence. It has the urgency of death in a country where everyday 750 people die needlessly of AIDS when treatment for their condition is readily available.⁷⁵
135. South Africa, happily, has moved much closer to the routine offer of HIV testing. But too many health professionals, as well as patients, continue to report that testing is still all too often withheld.
136. When this happens, the combination of internalised stigma, misconceived conceptions of autonomy and inappropriately enforced human rights protections may all too often prove lethal.
137. In my memoir, *Witness to AIDS* (2005), I recount the effect of my doctor subjecting my blood to an HIV test without consulting with me, and telling me on the phone about my positive diagnosis. He was wrong to do what he did. But in retrospect I suspect that what I needed was not less medical paternalism, but more of it. I needed to be guided to an HIV test, instead of having it sprung upon me. I needed to be counselled through its implications instead of being left alone and in the lurch late on a Friday afternoon. I needed to be embraced, supported and guided by a commitment to the best medical care, attention and expertise that was then available.

Conclusion

138. No doubt many health professionals are misguided and inappropriately intrusive. No doubt the rejection of paternalism and the interrogation of

⁷⁵ Mid-year Population Estimates 2010, *Statistics of South Africa*, Statistical Release PO302 released 20th July 2010. See also <http://www.statssa.gov.za>

medical beneficence has been wholesome. But when our bodies fail we are at our most vulnerable.

139. We need then to know that we can rely on a beneficent judgment that will value our interests in a way that, sometimes, our internalised terror of the truth disables us from realising.