FORUM

STIGMA, HUMAN RIGHTS, TESTING AND TREATMENT - TIME FOR ACTION

Ruben Sher Memorial Lecture, 26 November 2009

Edwin Cameron
Constitutional Court of South Africa

Ruben Sher came into my life at perhaps its darkest moment. I was diagnosed with HIV on a rainstorm-filled Friday afternoon in the second half of December 1986. My well-meaning doctor, who had not obtained my consent, phoned me with the bad news and left me in anguish, not only for the weekend but for the ensuing years.

His one act of solicitude in telling me that I was infected with HIV was to suggest that I contact Professor Ruben Sher at the South African Institute of Medical Research (SAIMR).

Uncounselled, unadvised and unsupported, I saw a grim future ahead. And indeed the ensuing years - years of fear, silence and inner shame - were hard.

My HIV diagnosis was shocking for two reasons. I was 33 at the time. I was building a growing practice as a human rights lawyer at a time of challenge and excitement. My diagnosis meant death. There was no cure for AIDS. Indeed, there was no treatment for it. Palliation was the best that medical science could offer. The mortality figures from North America and Western Europe, where the epidemic still seemed predominant, were horrific. By late 1986 perhaps half a million people had died of AIDS in North America alone - most of them, like myself, gay men in the prime of their lives. I had no doubt that death would overtake me soon.

The further reason why my diagnosis shocked me so was in many ways worse. It was the sense of shame, embarrassment, defilement and pollution I felt at being infected with HIV - possibly the most stigmatised disease in human history. I thought my shame stemmed from the fact that, only just out of the closet as an openly gay man, I had become infected with HIV.

But, as I was soon to discover, my shame and the stigma of AIDS had little to do with homosexuality.
I became involved in AIDS work not because of my own bodily engagement with the epidemic, but through my human rights work. And through it I met people who, seemingly very different from myself in that they were black and mostly women and mostly poor, nevertheless shared with me a sense of fear and horror at being known to have HIV.

In this bleakest time, I did follow my doctor's advice. I contacted Ruben Sher at the SAIMR. I well knew who he was. An avuncular Spike Milligan-like presence on TV, he had already assumed the role of a foremost public health commentator on AIDS. And he did not merely seem avuncular. He was in truth a voice of compassion and reason in the midst of an epidemic of stigma and fear.

While many of his clinical and academic colleagues - including surgeons at Baragwanath and some academics at Wits - called for isolation and compulsory screening, Ruben stood out as a voice of rationality and justice.

He made the obvious points - that HIV is difficult to transmit; that testing could be imprecise; and that there was no cure for those who sought to be diagnosed. But in times of panic the obvious is rarely stated. Ruben's courage and clarity and persistence in voicing the call for justice in dealing with the epidemic justify our honouring his memory this evening.

At one of the lowest points in my life, on a warm March day in 1987, I went to see him. He offered me kindness and reassurance and, importantly, utter confidentiality. He suggested that I be tested again. And when (inevitably) the test returned positive, he imparted the news, as such news should always be imparted, with gentle matter-of-fact kindness.

As the epidemic grew, Ruben and I started working together. He asked me onto platforms with him. We started being invited to speak together. We even trav-

This is an outline of a lecture delivered to the SA HIV Clinicians Society on 26 November 2009. The author is indebted to Nicholas Ferreira and Ting Ting Cheng for considerable help.

elled together. I remember one eccentric expedition to Tzaneen, where he and I were billeted in a luxury country lodge for the purpose of speaking to hundreds of farm workers and local officials about AIDS.

Working with Ruben could be trying. In fact, he could drive you nuts. He had a joke he invariably told. It was that you could get HIV whether you are heterosexual, homosexual, bisexual or trisexual. What is trisexual, Ruben would ask his audiences? He would confide triumphantly - it was someone who will try anything.

He had another joke. This one I like better. It was about a rich suburban lady who phoned him suspecting that her Malawian gardener had HIV. She confided to Ruben her fears about her proximity to him. Might he have infected me, she asked? His reply - according to him - was ‘Madam, when last did you have sex with your gardener?’

I greatly cared for Ruben and honoured his roles as an academic, as a crusader for right, as a caring clinician and as an astute physician. He gave me a gavel when I became a judge - but the symbol of dispensing to all alike without fear or favour was as appropriate for him as it was for my new job.

For tonight’s lecture I hope to meld the themes that entwined my own life with that of Ruben Sher - namely HIV infection, testing, stigma and shame.

FOUR SOCIAL FACTS - MASS SCALE, MEDICAL MANAGEABILITY, CONTINUING DEATHS, AND STIGMA

Four features of the AIDS epidemic stand out in any attempt to grapple with its social meaning.

- First, its scale. Even on recently adjusted lower estimates, AIDS is human society’s largest microbially borne pandemic for seven centuries - since one-third of Europe’s people died in the great plague of the mid-14th century. Estimates reckon that globally there are around 33 million people living with HIV or AIDS.[1] Of these the great majority (67% or 22 million in 2007) are in sub-Saharan Africa.[2] More than 13 million are black women, and roughly 2 million black children.[3] The total number of people who have died of AIDS is probably close to 30 million (in South Africa, according to the Actuarial Society of South Africa, 2.5 million).[4] Many more deaths are likely to come.
- Against this numbing volume of human fragility, suffering and death stands counterpoised a second fact - that infection with HIV is now fully medically manageable. The revolution that the arrival of treatment implied was not universally or immediately recognised.[5] But it was momentous. If diagnosed early enough, with properly administered combinations of antiretroviral (ARV) medications, the bodily progression of HIV can be stopped, and those sick with AIDS can be restored fully to life and health.

My presence here tonight - more than 12 years after I fell severely ill with AIDS - is evidence of the long-term success and sustainability of treatment. Perhaps the most important political fact about treatment is it works for poor and wealthy patients, in rural and urban settings, and in economically developed as well as undeveloped areas.[6] Given the shroud of horror that surrounded the disease in Western Europe and North America in its first 15 years, and still surrounds it almost everywhere else, this is still a radiant fact. But, as I will show, it continues to be insufficiently appreciated.

- Third, despite the medical manageability of the disease, and the fact that treatment for it - certainly compared with other long-term chronic conditions such as insulin-dependent diabetes - is relatively simple, and that it is increasingly available, millions of people are still dying of AIDS. Especially in Africa: in 2007, 1.5 million people died (75% of all AIDS deaths), 350 000 of them in South Africa. In any terms, this is monstrous: avoidable human suffering, unnecessary deaths, wasted lives.

But why are people still dying of AIDS in Africa and elsewhere when the disease can be easily managed?[7] Much death and illness can be ascribed to the developmental deficits of the locations worst affected: poor health care infrastructure, missing or poorly trained personnel, Africa’s burdens of disease (including other easily preventable and treatable diseases),[8] and poverty.

- But much is due to the fourth and most signal fact about AIDS - namely the stigma that surrounds it. It is this I want to talk about tonight: the fact that dying and suffering that is attributable to stigma persists in an epidemic of otherwise manageable disease.

STIGMA AND PUBLIC HEALTH/POLITICAL RESPONSES TO AIDS

Stigma is the mark of blame, rejection, disapproval and shame that society places on conduct and conditions that repel it or elicit its moral censure.

From the first day, society’s reaction to AIDS has been defined by stigma.

More than any other disease - more than leprosy, tuberculosis, and the black death, for all of which people felt understandable fear of contagion – HIV has been intensely stigmatised, even though its transmission occurs in known and narrow circumstances.[9]

It was stigma arising from its initial manifestation among gay men that led President Ronald Reagan to maintain what Randy Shilts called a 'ritualistic'[10] (and blameful) silence about AIDS, for six long years, from 1981 to 1987, implicitly conniving in the deaths of hundreds of thousands of men in the prime of their lives.

It was stigma, less than the rational pursuit of public health goals, that led countries as different as Sweden[11] and Cuba[12] to isolate and detain those with HIV.

And, perhaps most catastrophically, it was stigma that caused our own country's President Thabo Mbeki to question the viral aetiology of AIDS. He did so because he took umbrage at the notion of an epidemic of sexually transmitted disease manifesting in mass form among black Africans.[13]

For 28 years, stigma has pervaded and defined this epidemic. This triggered debate between those who advocated applying ordinary public health measures to the disease, and those who contended that this was inapposite and unjust.

Many argued that the disease should be treated by applying well-known public health principles – primarily in identifying, reporting and isolating those infected with HIV.

Yet HIV was different.

- First, for 15 long years doctors could do very little about it. They could offer only palliation. So diagnosis had strictly limited value.
- Second, a different approach was warranted because of the years of relative wellness that most enjoy before AIDS sets in, and because of difficulties (both technical and patient-related) in diagnosing infection.
- But the overriding – and most persuasive – argument for exceptional treatment of HIV was that society's reaction to it was exceptional.[14]

It was not the infectiousness of HIV, or its viral properties, or its morbid or mortal effects (for in this it was not intrinsically different from many other conditions) that made this disease different: it was stigma.[15]

It was stigma that necessitated anti-discrimination protections for those with HIV or suspected to have it, in medical care, housing, jobs, public facilities and anti-violence legislation.[16]

THE PARADIGM OF AIDS EXCEPTIONALISM

The ensuing debate resulted in a decisive victory for those who urged human rights protections for people with HIV/AIDS. The preponderant, if not quite universal, consensus among public health experts was that AIDS required special treatment. The only dissentients seemed to be policy deviants making ill-judged populist appeals – and even these proved mostly ineffectual.

In our own country, the African National Congress government came to power just as the epidemic seeped remorselessly southwards. In August 1994 it adopted a national AIDS plan that expressly espoused the international human rights consensus, and enacted a very sizeable body of legislation that protects the rights of those with HIV and prohibits unfair discrimination against them.[17] The courts have followed suit.[18]

The most eloquent voices justifying this approach were Dr Jonathan Mann[19] and later Justice Michael Kirby.[20] Their powerful advocacy of the 'AIDS paradox' – the notion that human rights protections for those with and at risk of HIV is an integral component of sound public health practice, and not its enemy – achieved not only moral, but intellectual predominance in virtually all places where international and national AIDS policy was made.

And rightly so. The wellspring of the AIDS paradox is stigma. Because of discrimination and ostracism people are reluctant to be tested, and hence cannot be reached for counselling, treatment and behaviour change interventions.[21] Traditional public health measures (mandatory testing,[22] partner notification, quarantine) merely fuel their fears, driving the disease underground, thus proliferating its spread.

The rational way out is therefore more, not fewer, human rights safeguards for those with HIV: to allay their fears, and to alleviate the horrific impact on them of abuses and malpractices. Only with its main bearers thus protected can the epidemic be rationally managed.[23]

Stigma, the source of the problem, was in this approach confronted obliquely – by protecting those with HIV from its effects; first, by shielding them from the terrifying invasion traditional public health approaches entailed; and second by enacting anti-discrimination protections to diminish the injustice of ostracism.

AIDS EXCEPTIONALISM AND BROADENING ACCESS TO TESTING

But the key practical product of the AIDS paradox, and perhaps its most telling achievement, lay not in warding off invasive public health measures, nor in the enactment of anti-discrimination laws. It took effect in the medical diagnosis of HIV. It was to hedge testing for HIV with significant prerequisites.

To test for HIV a health care practitioner could not assume consent: nor could it be implicitly, or even generally, given. It had to be explicit, and it had to be specific.

In many jurisdictions,[24] it had to be given in writing. In some, even written consent was not valid unless the test was preceded by statutorily prescribed counselling. In the pre-test counselling session, the counsellor had to warn the patient not merely of the medical implications of a positive diagnosis, but of its social repercussions - the discrimination and ostracism the patient would almost certainly face in consequence.

What is more, because of the risk that those choosing to test might be inferentially associated with HIV, testing had to be done in near-secret - at separate locations, on separate days, in unmarked (or code-marked) rooms. And special measures had to be taken to ensure that the resultant patient information was handled confidentially.

The unquestionable consequence of all this was massive disinducement to testing.

And not without reason. For as long as the major outcome of a positive diagnosis was ostracism, and for as long as doctors were powerless to offer more than palliation, there was little justification for exhorting those at risk to be tested. Its only point was to help them make better lifestyle and safer sex choices.

The disinducement was therefore warranted - and the AIDS paradox served us well for the epidemic's first 15 years.

In some parts of the world, it still serves us well. In the countries of South and East Asia, and in comparably affected regions, human rights activists continue to report that an HIV diagnosis too often provides an excuse for mistreatment, exclusion and denial of medical and other facilities. It remains primarily a badge of shame and a basis for ostracism (including the enactment of harsh criminal laws that target those with HIV).[25]

I can attest to these harsh realities, for they were vividly reported to me in Colombo in September 2007, and in Beijing in October 2008.

In these countries reluctance to testing for HIV remains understandable.

Yet the causes may lie in a distinctive epidemiological pattern. In countries such as India, China and Malaysia the epidemic remains overwhelmingly associated with groups that are still socially and politically marginalised - mainly men who have sex with men, commercial sex workers and intravenous drug users. Public health interventions and policy in these countries necessarily have to recognise this - also in relation to testing.

Yet, since the mid-1980s, the most striking demographic feature of the epidemic has been its racial and continental overload. Most people with HIV are Africans. And most of those dying of AIDS are Africans - more specifically, Africans in the Bantu-speaking regions of central and southern Africa.

In these regions, AIDS is a mass epidemic of heterosexually transmitted disease.

What is distinctive about this epidemic is not merely that the vectors of transmission are different - it is that its consequences are omnipresent.

It is impossible to ask any audience in central or southern Africa who among them have lost family members to AIDS, without a massed sea of hands rising in result. AIDS is everywhere, and its deathly impact presses on every household, every family, every workplace and every street.

And the worst is this. Despite the availability of treatment, despite the good news of its increasingly known efficacy, despite the knowledge of family support and despite legislative and social protections against discrimination, many people in Africa continue to contemplate testing for HIV with dread reluctance.[26] More than dread: deathly reluctance.

DISINCENTIVES TO TESTING

The fact is that many Africans experience stigma so intensely that they 'prefer' (if in such constrained circumstances one can speak of preferences) to die, rather than to be diagnosed with HIV.[27]

Part of this deathly dread stems from the external manifestations of stigma - the enacted discrimination, exclusion, dispossession and violence that are the social product of stigma; since undoubtedly well-warranted fear of discrimination by others inhibits many from choosing to be tested.

But a greater part, in my view, and perhaps the more crucial part, results from internal stigma. This is because too often the external stigma of AIDS finds an ally within - in internalised feelings of contamination, shame, self-revulsion, abasement, defilement and dread that those with HIV and at risk of it experience about themselves - even when they know they will receive acceptance and support from others.

Much of this, I suggest, derives from the fact that, overwhelmingly, HIV is a sexually transmitted disease: and we still poorly understand the intensity, intimacy, embarrassment and shame that our need for sexual connection - which seems to be inescapably human - occasions.[28]

A great deal has been written about external stigma; but surprisingly little - perhaps astonishingly little - about internal stigma. (In a review article in the issue of the journal *AIDS* published to coincide with the international AIDS conference in Mexico in August 2008, there was extensive discussion of stigma and its external manifestations, but no apparent recognition at all of its internal dimension.[29])

Internal stigma consists not of fear of discrimination or hostile treatment at the hands of peers or colleagues, or dread of others' reactions. It is something more opaque, and therefore difficult to confront. It is often stronger than a cognitive appreciation that friends, family and colleagues will offer love; it is stronger even than the knowledge that treatment is now readily accessible (even in many poor African countries). It ultimately proves stronger than the capacity to make life-affirming choices, because it paralyses them in favour of postponement, avoidance and death.

It is the most intractable part of stigma because it comes not from others, but springs from within. And it is more insidious, and more destructive, than external stigma, since it eludes the direct politically determined confrontation with which we fight discrimination.

The result of internal stigma is death, needless death, and its gross attendant human and social costs of suffering, bereavement and loss.

INTERNAL STIGMA AND OBSTACLES TO TESTING - THE ROLE OF HUMAN RIGHTS PROTECTIONS

Recognising stigma's internal dimension raises a new set of questions. These have been particularly hard for AIDS activists and human rights protagonists to confront.

If stigma stems not only from the hostile 'other', but partly from within those who themselves have HIV, we need new methods of understanding its origins and its effects. We need to understand with greater insight what we are combating.

Here I have made an inflammatory suggestion. It is that the very differentness attributed to AIDS, especially in the health care setting, is one of the principal causes of internal stigma, or at least powerfully underscores it.
The suggestion involves a provocative corollary: that the human rights protections, carefully and necessarily erected during the early stages of the epidemic to protect against discrimination, have themselves become a potent source of harm.[30]

Particularly in HIV testing, human rights safeguards have become harmful because they emphasise the differentness of AIDS. This reinforces internally those who are scared to test the exceptional, untoward, and distinctive features of AIDS.

Instead of people being diagnosed with mundane medical regularity, and steered towards treatment, diagnosis is hedged around with a fuss and palaver and hullabaloo that accentuates the feelings of self-disabling ignominy those at risk of HIV experience.

In the age of treatment - where AIDS can be medically managed, if only those suffering its effects can be reached timeously - this is a hideous cost.

We cannot without untruth deny or ignore the part that the protections erected against testing play in exacting this cost. Exceptionalism was a necessary response to the public ignorance, disdain, moralism and ostracism those with and at risk of HIV experienced; but it was also its logical counterpart.

Exceptionalism, born in reaction to stigma, has itself helped spawn stigma.

A new and grim equation must be inscribed on the wall of AIDS remembrance, a footnote to the activists' famously plangent equation in the 1980s that Silence = Death: the new equation is that Differentness = Death.

These considerations have given rise to acrid debate between those urging radical expansion of testing in mass-prevalence areas where treatment is available, and those who resist it.

The debate echoes that about AIDS exceptionalism in the 1980s. And its logical and formal premises have hardly changed: its essence still concerns the extent to which ordinary medical precepts and procedures should be applied to the management of HIV.

The contesting protagonists have changed. No longer, as in the 1980s, are the protagonists of de-exceptionalising the disease AIDS-ignorant policy wonks insensitive to its science and politics. They are experts who are themselves deeply versed in the clinical and human skills of AIDS treatment and prevention.

But, more significantly even, the factual setting of the debate has changed. The increasing availability of treatment is now the most important social fact about AIDS.

The test for AIDS policy is whether we can ensure that treatment effectively eclipses stigma, yet without sacrificing any single patient's right to choice, or to confidentiality.

And in this difficult quest, rigid policy positions are unefficacious and unhelpful.

On one side, those who support testing expansion point out that:

- 'Unlike other infectious diseases (e.g. syphilis, hepatitis B), for which consent for testing is implicitly assumed by virtue of medical consultation, and diagnosis is encouraged, the diagnosis of HIV infection has often been actively avoided. In many ways the approach to diagnosis of HIV infection has been more similar to that of an incurable genetic disorder than to an infectious disease'.[31]
- As a matter of fact, this analysis is incontestably accurate. Yet it provoked intensely ireful reaction.
- This was because of the same authors' assertion that 'the emphasis on human rights in HIV/AIDS prevention has reduced the importance of public health and social justice, which offer a framework for prevention efforts in Africa that might be more relevant to people's daily lives, and more likely to be effective'.[32]

On the other side, human rights advocates have resisted the medical 'normalisation' of HIV diagnosis, principally on the premise that expanded HIV testing infringes patient autonomy, and that it exposes those subjected to it to violation of their rights.[33]

Instead of radically and immediately increasing access to testing to diminish the deficit between treatment and death in Africa, we have been told that we must focus on the anxieties of 'the disempowered and still fearful ... by demanding investment in dignified health systems and protection from harmful social and legal effects of their health status being known'.[34]

The argument of those favouring expansion, that death is the ultimate rights violation, and that testing inhibitions collude with it, has not been acknowledged to have force against the motive forces of a 'real world' 'influenced by poverty-determined life choices, gender based violence, [and] fears of discrimination and stigma'.[35]

In this setting, human rights advocates have treated with suspicion or resisted:

- Rapid and more easily accessible forms of testing for HIV (including home-test kits) – currently, HIV tests are not available at the largest retail pharmacy chain in South Africa, Clicks Pharmacy, as well as Dis-chem Pharmacies, another large pharmacy chain. Yet home test kits are available for pregnancy, ovulation, prostate cancer, cannabis, and alcohol (breathalyser): some of the arguments against rapid access to testing are feeble, but some should justly be denounced as bizarre.[36]
- Legislation that compels mothers who might risk passing HIV to their babies to test for HIV so as to be able to receive prophylaxis that would reduce the risk.[37]
- The implementation of opt-out testing in Botswana (a mass-prevalence country where patients presenting for treatment at any public health facility have since 2002 been tested for HIV unless expressly refusing)[38] – even though evidence indicates that 'opt-in' requirements (where the patient must expressly choose to be HIV tested) cause deaths.[39]
- More recently, an article suggesting that universal ARV provision to everyone testing positive for HIV (using a mathematical model of HIV reduction in which everyone seroconverting to HIV is tested within a year) could be an important possible means of preventing and even eliminating endemic HIV dissemination,[40] triggered vigorous criticism from those concerned at its overly medicalist approach.

A group of respected human rights experts issued a statement complaining that the analysis did not address 'the issues of acceptability and safe applicability of universal testing and treatment in the face of widespread stigma and discrimination', and that it 'threatens to serve as justification for imposing mandatory HIV testing'.

This response seemed to me not only to miss the point of the mathematical model; it attributed an unconcern about rights protections to the authors which seems to me troublingly misplaced.[41]

It also failed to appreciate that the authors' argument finally unseamed one of the great canards of the epidemic, namely the supposed disjunct between treatment and prevention, by successfully telescoping the two into one overriding public health strategy.

In my view, we should immediately urge the Health Professions Council to adopt testing guidelines that permit for radically expanded testing.

In this regard, I commend the suggested minimum reasonable approach to testing that Nathan Geffen propounds for a busy, resource-stretched, but functional public health facility.

He suggests that the counsellor follows the following standard procedure with all patients who s/he judges have some risk for HIV:

'Ms X, I would like to proceed to give you an HIV test. If you have HIV, we can help you to live a healthy life because there are safe and effective medicines to treat you.'

At this point Ms X either says No (which is unlikely) or permits the blood to be drawn.[42]

To propound radically expanded testing - in this or other forms, including opt-out testing that does not even mention HIV specifically when a patient presents for general medical treatment - is not to ignore stigma (or to sacrifice confidentiality). It is to seek to mitigate it by more directly effective interventions than have hitherto been applied - including the beneficent effect of more widespread testing and diagnosis - as well as bringing home the fact that testing is a necessary first step to life-restoring treatment.[43]

It is here where recognising the role of internal stigma is critical. To see that stigma is not exclusively external, and that anxiety about testing is not solely about discrimination, is to open a vista of new, more flexible and supple policy positions, and more fruitful debate.[44]

Crucial to that is recognising the cost that human rights may now be exacting in fuelling stigma and in impeding access to testing and treatment.

This is not to decry the vital role of human rights activists in the past - or in the present: it is to question the focus of their engagement. The current trend toward enacting harsh criminal statutes in Africa, that specifically target people with HIV, seems to me a much more pressing and important issue than resisting expansion of treatment.

What is more, there has been a heavy shift of the weight of the argument in favour of expansion of treatment.[45] President Zuma, in a remarkable address to the National Council of Provinces on 29 October 2009, urged 'a massive mobilisation campaign' for testing. The President stated:

'Let me emphasise that although we have a comprehensive strategy to tackle HIV and AIDS that has been acknowledged internationally, and though we have the largest anti-retroviral programme in the world, we are not yet winning this battle. We must come to terms with this reality as South Africans. We must accept that we need to work harder, and with renewed focus, to implement the strategy that we have developed together. We need to do more, and we need to do better, together. We need to move with urgency and purpose to confront this enormous challenge. If we are to stop the progress of this disease through our society, we will need to pursue extraordinary measures. We will need to mobilise all South Africans to take responsibility for their health and well-being and that of their partners, their families and their communities. All South Africans must know that they are at risk and must take informed decisions to reduce their vulnerability to infection, or, if infected, to slow the advance of the disease.

'Most importantly, all South Africans need to know their HIV status, and be informed of the treatment options available to them. Though it poses a grave threat to the well-being of our nation, HIV and AIDS should be treated like any other disease.

'There should be no shame, no discrimination, no recriminations. We must break the stigma surrounding AIDS.'[46]

Common ground between testing expansionists and human rights proponents exists. It lies in their joint commitment to lessening AIDS deaths and human suffering. But harnessing the joint energy in service of those worst affected by the epidemic will require greater flexibility than has until now been evident.

Instead, until now, responses from human rights protagonists have seemed to suggest an overly defensive posture, reacting with alarm to creative new models and suggestions, rather than engaging constructively with them, in the light of the central and luminous fact that testing is the indispensable prerequisite to treatment and care, and thus that it embodies the difference between life and death.[47]

The AIDS epidemic has made the world sadder and older and perhaps wiser.

Some of what we have learnt from the epidemic is that due commitment to medical beneficence cannot always be assumed. We have also learned that technology and science alone will not provide answers if they ignore complex human reactions that spring from the material conditions of people's lives.

But suspicion about medical beneficence and reserve about technology's role does not justify rigid, inflexible and unresponsive defence of human rights protections that may have become outdated and inapposite.

Ruben Sher would have regretted the inaccurate characterisations and unproductive dichotomies that have resulted.

AIDS has been a heavy consciousness, burdening our beings and exacting, at least in Africa, a continuing daily price in grief and bereavement and mourning.

But in the end AIDS exacts its toll on human bodies.
If all could see that more clearly - those at risk of HIV no less than human rights activists and the medical

specialists eager to expand testing and thus save lives – we may begin to assert the primacy of the material and the rational over the shadow of stigma and misconception.

1. See UNAIDS Report on the Global AIDS Epidemic (hereinafter 'UNAIDS Report', at p. 33, available at http://data.unaids.org/pub/GlobalReport/2008/JC1510_2008GlobalReport_en.zip (accessed 21 October 2009).
2. *Idem* at p. 30.
3. *Idem* at p. 33 (globally, there are 2 million children (under 15) living with HIV, of whom almost 90% live in Africa).
4. http://www.actuarialsociety.org.za/Portals/1/Documents/ab739d74-e6fe-483f-b205-718f20195c12.xls; see also on the website of the Treatment Action Campaign http://www.tac.org.za/community/keystatistics. There are an estimated 5.7 million people in South Africa living with HIV in 2007, making this the largest HIV epidemic in the world. UNAIDS Report above at p. 40.
5. See the sceptical, even pessimistic, approach of Catherine Campbell, *Letting Them Die: Why HIV/AIDS Prevention Programmes Fail* (Indiana University Press, 2003), p. 5 ('there is little hope of pharmaceutical solutions being available in ways that can be affordably and effectively implemented in the short-term future by many of the poorest countries where HIV flourishes'), and p.19 (while ART has a role in 'reducing the immensity of the suffering of those who have already been infected, and of their loved ones and careers', 'on their own they neglect the needs of the majority who are not yet infected'); and more recent but comparable scepticism in Helen Epstein's *The Invisible Cure: Why We Are Losing The Fight Against AIDS in Africa* (Picador, 2008).
6. Since 1986 Partners In Health and Zanmi Lasante have provided HIV care in squatter settlements in rural Haiti: see 'Scaling-up HIV treatment programmes in resource-limited settings: the rural Haiti experience', Koenig, Leandre and Farmer, available at http://www.pih.org/inforesources/Articles/AIDS_2004_Koenig-et-al_Scaling_up_HIV_treatment.pdf; Farmer *et al.*, 'An information system and medical record to support HIV treatment in rural Haiti', available at http://groups.csail.mit.edu/medg/people/hamish/hiv-emr-bmj.pdf; also joint partnerships between Médecins sans Frontières (MSF) and the Department of Health in South Africa such as the HIV/AIDS programme in Lusikisiki, Eastern Cape, available at http://www.msf.org.za/docs/lusikisiki_final_report_2006.pdf; the 2000 joint programme in Khayelitsha, Western Cape, 'Comprehensive HIV service development at primary care clinics', available at http://www.msf.org.za/docs/Khayelitsha_report_July_2005.pdf. Experience in countries including Botswana, Tanzania, Thailand, Brazil and Zambia indicates that policy on health care funding can be adjusted to eliminate user charges for HIV treatment, helping to overcome socio-economic barriers and increasing rates of long-term adherence to medication, see 'Progress on global access on antiretroviral therapy, a report on '3 by 5' and beyond', March 2006, available at http://www.who.int/hiv/fullreport_en_highres.pdf.
7. According to a 2008 World Health Organization report, 'Towards universal access: Scaling up priority HIV/AIDS interventions in the health sector', 2.9 million people are receiving ARV therapy in sub-Saharan Africa, while 6.7 people need it. Worldwide, 4 million people have access to ARV therapy, while 9.5 million lack access. Available at http://www.who.int/hiv/pub/tuapr_2009_en.pdf (accessed 22 October 2009). The number of new HIV infections continues to outstrip the increase each year in the number of people on ARV therapy by 2.5 to 1 (UNAIDS report). For South Africa, then health minister Barbara Hogan told SABC radio news on Wednesday 28 January 2009 that 700 000 were on ARV treatment: http://www.iol.co.za/index.php?set_id=1&click_id=125&art_id=nw20090128183422743C506795 (accessed 31 January 2009) - but UNAIDS estimates that 1.3 - 2.1 million South Africans need treatment now.
8. Such as tuberculosis, measles and syphilis - see appendix to Helen Epstein's *The Invisible Cure: Africa, the West, and the Fight against AIDS* (Farrar, Straus and Giroux, May 2007).
9. Stigma (a process model): 'Disease stigmatisation can be defined as a social process by which people use shared social representations to distance themselves and their ingroup from the risk of contracting a disease by (*a*) constructing it as preventable or controllable; (*b*) identifying 'immoral' behaviours in contracting the disease; (*c*) associating these behaviours with 'carriers' of the disease in other groups; and (*d*) thus blaming certain people for their own infection and justifying punitive action against them' (Deacon, *Understanding HIV/AIDS Stigma.* Cape Town: HSRC Press, 2005, p. 23).
10. Randy Shilts, *And the Band Played On: Politics, People, and the AIDS Epidemic* (Stonewall Inn Editions, 1987), p. 588.
11. See Danziger R, 'HIV testing and HIV prevention in Sweden' (*British Medical Journal* 24 January 1998), available at http://findarticles.com/p/articles/mi_m0999/is_n7127_v316/ai_20303083/pg_2 (accessed 31 January 2009).
12. Hansen H, Groce N, 'Human immunodeficiency virus and quarantine in Cuba' (*JAMA* 2003; 290: 2875), available at http://jama.ama-assn.org/cgi/content/full/290/21/2875 (accessed 31 January 2009).
13. See Nicoli Nattrass, *The Moral Economy of AIDS in South Africa* (Cambridge University Press, March 2004), *Mortal Combat: AIDS Denialism and the Struggle for Antiretrovirals in South Africa* (University of Natal Press, July 2007), and *Denying AIDS: Conspiracy Theories, Pseudoscience, and Human Tragedy* (Springer Verlag, February 2009) co-written with Seth C Kalichman.
14. Ronald Bayer, 'Public health policy and the AIDS epidemic. An end to HIV exceptionalism?' (*N Engl J Med* 1991; 324: 1500-1504); see also Ronald Bayer and Claire Edington, 'HIV testing, human rights, and global AIDS policy: Exceptionalism and its discontents' (*Journal of Health Politics, Policy and Law* 2009; 34(3)).
15. Wynia MK, 'Routine screening: Informed consent, stigma, and the waning of HIV exceptionalism' (*Am J Bioethics* 2006; 6(4): 5) explains AIDS exceptionalism as 'the notion that being diagnosed with HIV is so different from any other diagnosis that it must be handled very differently. There should be exceptional confidentiality protections, because the information involved is so sensitive; exceptional informed consent, because the test is so personally invasive; and exceptional caution prior to testing, since a positive result can be so disruptive'. It has rightly been pointed out that this view of HIV testing in particular derives from the genetic counselling model of testing for untreatable conditions, which no longer applies: Frieden TR, *et al.*, 'Applying public health principles to the HIV epidemic' (*N Engl Med J* 2005; 335: 22: 2397).
16. Titles I and II of the Americans with Disabilities Act (ADA) protects individuals with disabilities from discrimination in employment and in the enjoyment of all public entities such as schools, doctors' rooms and shopping malls. The express intent of the ADA was to define 'disabilities' broadly (see *Board of Nassau County v. Arline*, 480 U.S. 273 (1987); and in the ADA Amendments Act of 2008). Similarly to Title I of the ADA, the US Rehabilitation Act of 1973 prohibits discrimination on the basis of disability in programmes conducted by Federal agencies, in programmes receiving Federal financial assistance, in Federal employment, and in the employment practices of Federal contractors.
17. The Labour Relations Act 66 of 1995 prohibits unfair labour practices (including against job applicants) on grounds of 'disability'; the Employment Equity Act 55 of 1998 specifically mentions HIV status as a prohibited ground of unfair discrimination and prohibits testing of employees and job applicants for HIV status unless the Labour Court determines it justifiable; the Code of Good Practice on HIV/AIDS and Employment was approved by the Southern African Development Community (SADC) in September 1997 and a Ministerial Code of Good Practice on HIV/AIDS and Employment was promulgated in terms of the Employment Equity Act 55 of 1998 on 1 December 2000; the Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000 prohibits unfair discrimination on the grounds of 'disability' (which was anticipated to include HIV/AIDS, but is not expressly so defined), contains directive principles on HIV/AIDS, establishes an 'Equality Review Committee' and requires the Minister of Justice and Constitutional Development to give special consideration to the inclusion of, among others, HIV/AIDS as an expressly prohibited ground of discrimination (the ERC in 2006 apparently recommended to the Minister of Justice that 'HIV/AIDS status' be formally included under the listed grounds of discrimination in the Equality Act); the Medical Schemes Act 101 of 1998 includes HIV-related diseases as a category benefiting from 'Prescribed Minimum Benefits', provides for the compulsory cover of medical and surgical management of opportunistic infections, and prohibits denial of membership on the basis of 'disability or state of health'; the National Health Act 61 of 2003 provides for the introduction of a 'National Policy on Testing for HIV' (the policy was published in August 2000), describes the circumstances under which HIV testing may be conducted and sets out requirements for pre- and post-test counselling and informed consent; the National Education Policy Act 27 of 1996 provides for the drafting of national policies on educators and learners - the Minister of Education in August 1999 issued a 'National Policy on HIV/AIDS for Learners and Educators' which prohibits unfair discrimination against learners, students and educators with HIV/AIDS.
18. See *Hoffmann v South African Airways* 2001 (1) SA 1 (CC).
19. Justice Kirby correctly credits Jonathan Mann with initiating the human rights approach in the epidemic - see 'The never-ending paradoxes of HIV/AIDS and human rights' (*African Human Rights Law Journal* 2004; 163, 165f).
20. Justice Kirby explains his engagement with the epidemic, and the first paradox, in 'The never-ending paradoxes of HIV/AIDS and human rights' (*African Human Rights Law Journal* 2004; 163).
21. As Justice Kirby puts it, the first paradox was necessary 'because only behaviour change could curb the spread of HIV, and a human rights-based approach was regarded as the most feasible way to ensure the knowledge of an means to effect the behaviour change': 'The never-ending paradoxes of HIV/AIDS and human rights' (*African Human Rights Law Journal* 2004; 163).
22. 'WHO and UNAIDS have asserted that there is no public health justification for mandatory HIV screening as it does not prevent the introduction or spread of HIV' (UNHCR '10 key points on HIV/AIDS and the protection of refugees, IDPs and other persons of concern', 12 April 2006), available at http://www.unhcr.org/444e20f32.html (accessed 20 November 2009).
23. See Anand Grover (UN Special Rapporteur), '[r]ight of everyone to the enjoyment of the highest attainable standard of physical and mental health', paras 26 - 27, submitted to the UN General Assembly 64th session, 10 August 2009: 'Importantly, a rights-based approach addresses structural barriers to achieving informed consent within the appropriate health-care continuum. Such an approach is especially cognizant of the power imbalances resulting from inequalities in knowledge, experience and trust between the health-care provider and the individual, particularly those from vulnerable groups. Importantly, stigma and discrimination serve as disincentives for such patients to seek out services ad providers to treat patients equally. 'Compulsory, and, at times, routine testing is disempowering and frequently compromises human rights. Such testing is coercive and generally results in inadequate provision of information and counselling, compromising informed consent and deterring individuals from accessing test results and appropriate services.'
24. In the United States, for example, eight states currently require written consent for HIV testing - New York, Massachusetts, Wisconsin, Nebraska, Rhode Island, Pennsylvania, Michigan, and Alabama. However, bills are currently pending in the New York and Massachussetts state legislatures eliminating written consent for HIV testing. California and Illinois eliminated their written consent requirement in 2008.
25. See Burris S and Cameron E, 'The case against criminalization of HIV transmission' (*JAMA* 2008; 300(5): 578-581); see also my address, Criminal statutes and criminal prosecutions in the epidemic: help or hindrance? at the 17th International AIDS Conference, August 2008, Mexico City; Lawrence K Altman, 'Seeking better laws on HIV', *New York Times*, 8 August 2008, available at http://www.nytimes.com/2008/08/09/health/09aids.html?_r=3&oref=slogin&ref=world&pagewanted (accessed 21 October 2009); Rebecca Wexler, 'Criminalization of HIV', International Relations and Security Network, 27 August 2008, available at http://www.isn.ethz.ch/isn/Current-Affairs/Security-Watch/Detail/?id=90570&lng=en (accessed 21 October 2009).
26. I explore some of this in my Ronald Louw Memorial Lecture (May 2006), 'Normalising testing, normalising AIDS' (*Theoria*, April 2007, pp. 99-108).
27. See Jonny Steinberg, *The Three-Letter Plague* (US title *Sizwe's Test*) (Simon & Schuster, February 2007).
28. This I try to grapple with in chapter 2 of *Witness to AIDS* (Tafelberg, 2005).

29. Anish P, *et al.*, 'Stigma in the HIV/AIDS epidemic: a review of the literature and recommendations for the way forward' (*AIDS* 2008, 22 (suppl 2): S67-S79). It is notable that the foundational work of Erving Goffman (1922-1982), which the authors cite (from Stigma*: Notes on the Management of Spoiled Identity* (1963)) does recognise that 'the social label of deviance *compels stigmatized individuals to view themselves* ... as discredited or undesirable' - yet there is no explication in the context of AIDS of this vital 'self-viewing' aspect. See also Robert Crawford, 'The boundaries of the self and the unhealthy other: Reflections on health, culture and AIDS' (*Soc Sci Med* 1994; 38(10): 1347-1365).
30. Compare, recognising this point, De Cock KM, *et al.* (2002) 'Shadow in the continent: public health and HIV/AIDS in Africa in the 21st century' (*Lancet* 2002; 360: 67) at p. 69 ('Paradoxically, treating HIV/AIDS as being different from other infectious diseases probably enhances stigma rather than reduces it. The emphasis that has been placed on anonymity for HIV-infected people, which is different from confidentiality and analogous to secrecy, might also have been counter-productive. Anonymity is impossible to maintain as immune deficiency progresses'); and Frieden TR, *et al.* 'Applying public health principles to the HIV epidemic' (*N Engl J Med,* 2005; 335: 22: 2397) at p. 2398 (suggesting that targeting HIV testing at those perceived to be at risk may perpetuate stigma).
31. De Cock KM, *et al*., 'Shadow in the continent: public health and HIV/AIDS in Africa in the 21st century' (*Lancet* 2002; 360: 67-72), at p. 68.
32. *Idem.*
33. A recent statement, 'Civil society statement on ART as prevention: Scaling down HIV requires scaling up human rights, testing and treatment', submitted to the participants at the WHO consultation on ART as HIV prevention (available at http://www.icaso.org/resources/2009/ART_statementEN.pdf, accessed 20 November 2009), states: 'We urge UN bodies, donors and researchers involved in this exploration to be mindful that people living with HIV and many who are highly vulnerable to it remain unable to gain access to HIV testing and to initiate treatment earlier, in a timely fashion, as a result of many human rights violations, as well as clinical and systemic barriers. Research models that do not adequately consider and address these barriers do a disservice to the important goal of making ART available to all as both prevention and treatment.

    'It is neither desirable *nor possible* to scale up voluntary HIV testing and treatment sustainably to implement ART as prevention without addressing these human rights, clinical and health-systems challenges. Supporting and strengthening civil society organizations in affected communities in the work of creating enabling environments are crucial to achieve this goal.

    'Any feasibility study or pilot study of ART as prevention must include an assessment of the social, policy and legal framework to address impediments to human rights protections and barriers to testing and treatment uptake before the study proceeds.'
34. Mark Harrington (Executive Director of Treatment Action Group) blog post on the Critical Path AIDS Project, 4 December 2008, in response to web discussions regarding the Granich article ('Universal voluntary HIV testing and immediate antiretroviral therapy', Lancet March 2009). The blog post is available at http://critpath.org/pipermail/healthgap_critpath.org/2008-December/000513.html (accessed 21 October 2009).
35. *Idem.*
36. Some AIDS activist organisations oppose rapid home-test kits on the basis that counselling would be absent, and that those testing positive might react unpredictably; already suggested presciently a 1997 *Lancet* article by Merson MH, *et al*., 'Rapid self-testing for HIV' (*Lancet* 1996; 348: 352-353); yet see 'SA HIV home test kits withdrawn' (24 May 2005), available at http://news.bbc.co.uk/2/hi/africa/4576179.stm (accessed 21 October 2009); Natasha Joseph, 'Student devastated by home HIV test result', 30 October 2007, available at http://www.iol.co.za/index.php?set_id=1&click_id=125&art_id=vn20071030055441964C325889 (accessed 21 October 2009); http://www.avert.org/testing.htm ('AVERT opposes the legalisation of the sale of home testing kits in the UK because of the lack of post-test counselling'); 'Risks associated with home-use medical tests', Health Canada, available at http://www.hc-sc.gc.ca/hl-vs/iyh-vsv/med/medtest-eng.php#ri (accessed 21 October 2009) ('There is also a significant chance that people may interpret test results incorrectly and/or decide to change their treatment or lifestyle unnecessarily, if they don't consult a qualified health care provider. Interpretation of test results should always be part of a comprehensive health assessment').
37. See the debate between Chersich and Richter and Scorgie *et al.* in M. Chersich M and Richter M, 'HIV testing and ARV prophylaxis for newborns without their mothers' consent', *Southern African Journal of HIV Medicine,* Autumn 2008, pp. 6-8; and rebuttal by Scorgie F, Filiano BA and Shapiro K, 'Coercive policies do not make for better health outcomes', *Southern African Journal of HIV Medicine,* Autumn 2008, pp. 8-9.
38. Because about one-quarter of those with HIV in the USA are still undiagnosed, the Centers for Disease Control (CDC) has now published guidelines recommending routine HIV testing in all heath care settings in patients between 13 and 64 years, the patient being told that testing is done unless patients opt out - separate signed consent and prevention counselling are no longer required. (Lifson AR *et al*., 'Routine opt-out HIV testing', *Lancet* 2007; 369: 539-540.)
39. See 'Reduction in HIV testing due to opt-in consent linked to significant loss of life' (31 October 2009), referring to research findings by Michael April *et al*., available at http://www.infectiousdiseasenews.com/article/50172.aspx (accessed 20 November 2009).
40. Granich RM, *et al*., 'Universal voluntary HIV testing with immediate antiretroviral therapy as a strategy for elimination of HIV transmission: a mathematical model' (*Lancet* 2009; 373: 48-57).
41. See 'Testing millions', a message from AIDS Healthcare Foundation President Michael Weinstein (available at http://www.testingmillions.org/):

    'We at AIDS Healthcare Foundation (AHF) believe that the best way to reach the estimated 33 million people living with HIV/AIDS is to identify those who do not know they are infected and link them to treatment. This is also the best route to combating the spread of the disease, as it is believed that the source of the majority of new infections are people who are HIV positive, but do not know it.

    'Clearly, testing in much greater numbers is urgently needed. AHF's Testing Millions campaign is designed to not only increase testing, but also to establish a new, more streamlined testing model that - if widely adopted - could result in a dramatic drop in new infections and deaths.'
42. Nathan Geffen's proposal continues: The counsellor then does the test. If it comes back negative, s/he tells Ms X that she's HIV-negative. If and only if s/he has time, the counsellor also gives her some condoms and informs her that using condoms during sex is a good way to reduce the risk of contracting HIV. If the test comes back positive, the counsellor explains in a few minutes the following:
    - That Ms X needs to have a CD4 and viral load test every X months and what these measure.
    - When Ms X's CD4 drops below 350, Ms X must start ARV treatment which involves taking one pill (maybe two) once daily for the rest of her life.
    - Ms X can continue to have sex using condoms.
    - Ms X can have a child if she chooses, but she will need to take measures to reduce the risk of the child contracting HIV. (The same goes for a Mr X.)
    - Counsellor refers Ms X to a treatment literacy class/support group/structure of some kind.
    - Counsellor informs Ms X that if she is distressed or confused, she can contact him/her for further counselling.
43. See 'Reduction in HIV testing due to opt-in consent linked to significant loss of life', *Infectious Diseases News* 31 October 2009, available at http://www.infectiousdiseasenews.com/article/50172.aspx.
44. I am indebted to Gregg Gonsalves (private communication, 4 February 2009) for the following perceptive comments: 'The fear of death and the fear of lack of access to treatment constitute an important aspect of the internal stigma and present a substantial barrier to consent to testing. The fear of testing stems from a deep psychological desire to avoid the knowledge that one has been infected with the disease and is therefore dying, compounded by the lack of knowledge of treatment and whether treatment will be available. In addition, the nature of the calculation that one makes relating to one's relationship with death or behavior feeds into fear and internal stigma.'
45. Federal health officials in the United States will conduct a study implementing the strategy 'Test and Treat' in two locations with some of the country's highest HIV infection rates, Washington, DC and the Bronx. The goal is to stop the spread of HIV by routinely testing virtually every adult in the community and providing prompt treatment to those who test positive. This is a first step not to measure whether the programme actually works to slow the epidemic, but to find out whether such a strategy can even be carried out given the many obstacles to testing and treatment. Susan Okie, 'Fighting HIV a community at a time', *New York Times* 27 October 2009, available at http://www.nytimes.com/2009/10/27/health/27hiv.html (accessed 20 November 2009).
46. Available at http://www.tac.org.za/community/files/PRES%20ZUMA%20ADDRESS%20TO%20NCOP%20291009.pdf (accessed 20 November 2009).
47. Granich *et al.* do not, as has been claimed, give 'unexamined endorsement [to] annual universal testing': rather, they pose a hypothetical question - if there were such testing, and immediate antiretroviral therapy, would endemic HIV transmission cease; and their suggestive - hopeful - answer is yes. See the discussion on AIDSMAP of the Granich *et al.* article, available at http://www.aidsmap.com/cms1282664.aspx (accessed 20 November 2009): '[u]niversal testing and treatment is only likely to be cost-effective in settings where HIV is hyper-endemic and where AIDS seriously threatens long-term stability and growth. Further cost-effectiveness analysis will be needed. The WHO analysis looks at the relative costs of pursuing the universal approach *or* treating people when their CD4 count falls below 350 cells/mm^3. The universal approach demands substantially greater expenditure during the first two decades, but begins to become cheaper than the default treatment approach by 2030. This balance and time-scale may differ in other countries in the southern Africa region.' For criticism of the Granich hypothesis, see Dr Geoffrey Garnett, from Imperial College London, in a commentary piece published in *The Lancet*: 'At its best, the strategy would prevent morbidity and mortality for the population, both through better treatment of the individual and reduced spread of HIV. At its worst, the strategy will involve over-testing, over-treatment, side effects, resistance, and potentially reduced autonomy of the individual in their choices of care.'

    Imogen Foulkes, 'Universal test "would slash AIDS"', BBC News 26 November 2008, available at http://news.bbc.co.uk/2/hi/7749437.stm (accessed 20 November 2009).