Human dignity is identified as the bedrock of freedom, and is of prime importance to the study of food insecurity.
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159 Centre for the Study of AIDS
This is the ninth AIDS Review published by the Centre. These Reviews are regarded as some of the most critical and interesting writing about HIV and AIDS in South Africa. They are widely prescribed as core reading in university courses in the United States of America, the United Kingdom, Australia, India and Brazil. All of the Reviews have had more than two print runs and what they provide is a challenge and critique to the conventional wisdoms that have developed around HIV and AIDS, and the ways in which issues raised by the epidemic should be addressed. There is a troubling orthodoxy in many of the HIV and AIDS responses and the main function of the Reviews is to address this orthodoxy that tends to stifle debate and dissent.

Past Reviews have taken the issues of human rights, sexuality and masculinities, food security, care and support, the political response, families and education and placed them under scrutiny. Balancing acts looks at the ways in which public health and human rights have often been pulled into tension in dealing with HIV and AIDS and other related health issues.

Kevin de Cock writing in his comment in The Lancet in 2002, entitled ‘Shadow on the continent’ said that how an issue is defined strongly affects how it is addressed. Portrayal of HIV/AIDS against a background of either human rights, poverty, gender or public health elicits different responses, but the measure of each response must be its ability to curtail the epidemic, and at what social cost.

In essence this is what this Review is about. How do we best understand what works, how do we estimate and measure the social cost, quite apart from the economic and political costs, and how do we strike the balance between the imperatives of public health on the one hand and the imperatives of human rights on the other?

This tension between public health and human rights arises from the ways in which HIV and AIDS have been and still are defined. As the epidemic unfolds and evolves the limits of previous and existing interventions and philosophies become clearer and the dangers of new ones become more acute. Thinking about the epidemic has to change and has to adapt as the circumstances of those who are grappling with living with HIV, or trying to remain uninfected, change. While human rights operate globally, public health – while being discussed in sweeping global assertions about, for example, testing or circumcision – has to be implemented
and understood locally. The sweeping global assumptions of public health – the emphasis on rationality, on measurement, on numbers, on infrastructure and on results, sit uneasily with the irrationality that drives people’s lives, their understandings of their own autonomy and agency and their ability to understand and act on the public health messages. It is this tension between what makes sense as a ‘neutral’ public health intervention, and the failure of people to act in ways that would make the intervention a success, that suggests that an emphasis on human rights is inappropriate (and that in cases of crisis and emergency they can be reduced or even ignored).

To ensure that people understand their rights and how to act on them, it is important to develop notions of legal capital. The concept of legal capital, developed by the Centre for the Study of AIDS, is based on ideas drawn from the concept of social capital. Social capital is a form of social cohesion and is central to the health of societies, because it brings people together to contribute to shared goals which promote connection, ethical values and human life.

Legal capital is a form of social cohesion based on a knowledge of, and confidence in, the law and the human rights framework in a society, as well as the attainment of these rights. Recognising and realizing these rights would be seen as intrinsic to the full attainment of humanity. Legal capital exists when there are human rights networks between community members, the state and civil society organisations and the existence of legislation and policies which, if implemented and enforced, would change the lives and experiences of individuals and communities.

High levels of legal capital would exist when there are positive connections between para-legal organisations, the police, the courts, community-based organisations and community members, when community members are aware of their rights and how to access them, and when there is consensus on the importance of human rights and their role in building a fair and equitable society. It is supported when the justice system is user-friendly to ordinary community members who feel that justice can be done and they have a sense of trust in the law.

Most importantly legal capital operates to create the environment where the law is seen as enabling and building, rather than punishing and breaking down, and is seen to bring about meaningful change in a community – and legal decisions do not get mired in policy or bureaucratic logjams.

Central to this is social, political and legal integrity, respect for the law at all levels and an intolerance of the
abuse of power vis à vis the law, policies, health, clients or patients. It is very important that people accessing health facilities are not disempowered by health professionals and officials, and know what their rights are and how to exercise them. Public health calls to reduce these rights in the face of an overwhelming emergency (which is how people like to define the AIDS epidemic) must be resisted. Instead, there needs to be a system where the emergency response is firmly embedded in the rights of all people. This becomes an inclusive health response rather than one that alienates people and makes them reluctant to use the services.

Public health and human rights violations flourish in societies that are dishonest in fundamental ways and where social integrity is lost. Balancing human rights with public health is about restoring integrity and having the courage to challenge areas where public health interventions are likely to have a direct impact on human rights, or personal dignity and integrity.

The views expressed in this Review are solely those of the author and the Centre for the Study of AIDS.

Mary Crewe

Director, Centre for the Study of AIDS

AIDS Reviews

2000 – To the edge by Hein Marais
2001 – Who cares? by Tim Trengove Jones
2002 – Whose right? by Chantal Kissoon, Mary Caesar and Tashia Jithoo
2003 – (Over) extended by Vanessa Barolsky
2004 – (Un) Real by Kgamadi Kometsi
2005 – What’s cooking? by Jimmy Pieterse and Barry van Wyk

Buckling by Hein Marais (an extraordinary Review)

2006 – Bodies count by Jonathan D. Jansen
2007 – Stigma(ta): Re-exploring HIV-related stigma by Patrick M. Eba
2008 – Balancing Acts by Carmel Rickard (A collection of documents supporting this Review is available at www.csa.za.org under the ‘Downloads’ section)
Introduction: Balancing acts

Fighting the fear of AIDS, it seems, is as important as fighting the disease itself ... As researchers attempt to conquer this disease called AIDS, public officials attempt to conquer the epidemic of fear ... It is a delicate balancing act, raising the level of concern for the disease on the one hand, while reducing the level of panic on the other.

– ABC, June 20, 1983

As the HIV and AIDS epidemics have unfolded in South Africa and the epidemic has become a generalised one, increasing tensions have developed between what is called the ‘public health approach’ and the ‘human rights approach’. This tension has arisen because despite two decades of education and awareness, increased services, and high numbers of people living with HIV and AIDS there still seems to be no real progress in changing behaviour and turning the rate and pace of infection. This has led increasingly to the re-medicalisation of the response and the introduction of measures aimed at increasing prevention that are driven by a public health agenda, for example the Three by Five testing and treatment programme, and male circumcision.

Increasing tensions have developed between what is called the ‘public health approach’ and the ‘human rights approach’.

How is it possible that in the AIDS world various positions, for which there is very little evidence or which clearly violate human rights, come to be taken as comprising authoritative, and therefore to some degree socially determinant, statements about the nature of the world and the ways to address the epidemic?

This Review address some of the examples of decisions being reached where the initial intention may be to serve one purpose but the effect may be an inadvertent abuse of human rights.

The oath taken by medical practitioners to first do no harm has generally been applied to medical procedures but now it needs to be expanded to a wider social ambit – in all our responses to HIV and AIDS through medicine, law, social policy and political actions – the fundamental premise of first do no harm should underpin all work and be the measure against which we judge all responses, public health and human rights.

HIV and AIDS have provided a serious challenge to the ways in which public health practitioners – doctors, nurses and policy-makers – operate. Traditionally they have been
used to being able to control illness and health, yet the ways in which the epidemic has unfolded have rendered traditional medical interventions largely unsuccessful in ensuring widespread behaviour change and ‘compliant’ patients. It was believed that with rising numbers of infections, increasing numbers of people dying and high levels of pain and suffering, people would understand the need to reduce transmission and so change their behaviour. The initial frustration was fuelled precisely by the absence of drugs. Doctors felt helpless and were forced back into a default position they were less familiar with – that of talking to their patients, listening and understanding the ways in which their life circumstances affected their ability to make choices. Early on in the epidemic the issue of HIV testing raised difficult questions for public health: the issues of confidentiality, respect for the doctor-patient relationship and the need to inform. This was one of the earliest tensions – and has remained a tension ever since – and it has pushed the belief in universal testing, as well as calls for an end to confidentiality, and for openness and disclosure.

Since the most vocal group at the receiving end of these attitudes was well-educated middle-class men, there was a groundswell of rejection of calls for disclosure and an emphasis on confidentiality and testing. These are fundamental principles to which many people remain committed, believing in the fundamental right of people to choose, the right to privacy and the importance of counselling and support. The calls to reduce counselling, to make routine offers of testing, to disclose and to provide male circumcision are all reflections of the frustrations of those who wished to believe that when people were given enough information they would sensibly and rationally change their behaviour. These comments were driven by ‘AIDS panic attacks’ that called for increasing measures away from personal autonomy and agency in order to reduce infection and to save lives. The tension remains: between those who believe that testing, disclosure and circumcision will save lives and those who ask that these interventions be accompanied by good social research.

Medical interventions can only be effective when the lives of people affected by this epidemic are well understood.

Medical interventions can only be effective when the lives of people affected by this epidemic are well understood. What are the forces that operate in society? What are the social, cultural and sexual beliefs that people have? How do they understand disease, death and dying and how do they view their place and role in the world? Much of the failure of the response to AIDS lies in the ways that public health practitioners and medical professionals view their role in society and the ways in which they view their fellow citizens. However, there is also a failure to seriously interrogate how human rights work in a fractured society, and how social and legal capital is
developed. Furthermore, there is a no sophisticated, theoretically informed understanding of the kinds of societies we inhabit and how we are constructed by those societies as individuals, as social and sexual beings and as citizens.

A TALE OF TWO CITIZENS

A short story describing the experiences of two South Africans highlights the very different access and understanding citizens in South Africa have to health care, human rights and to legal capital. The protagonists are both adult citizens and yet their experiences of power, control and support differ enormously, although at times they collapse into a shared experience. It is a very familiar South African story: an illiterate person lacking a developed notion of the autonomous self and how to demand and exercise his rights, and his employer, well educated, well versed in the law, powerful, able to demand those rights, and demand them on behalf of another.

Yet, in the face of the complexity of the issues surrounding illness, HIV testing and diagnosis and subsequent events, the empowered citizen is also rendered powerless at times, as public health imperatives take over and control events in ways that neither of them like and which are desirable for neither.

Despite the apparent overtones of patronage, what this story highlights is the tension between public health and human rights. Johannes, the illiterate citizen, had rights in public health but not the education or necessarily the confidence needed to access them easily – and yet at times his rights were both violated and protected. Peter, the storyteller, had rights too and enough legal capital to exercise them and know-how to claim them for another. Yet at times, Peter felt shut out by the ways in which the public health system interprets rights, obligations and confidentiality.

The empowered citizen is also rendered powerless at times, as public health imperatives take over and control events.

Two citizens who should be equal in the eyes of the law and the health care system – two citizens with very different expectations and experiences of human rights and public health.

This AIDS Review, Balancing Acts, starts with this familiar tale and looks beyond that at how human rights and public health are in tension in a range of other settings and how this affects the ways in which people understand HIV and AIDS: what are people’s rights and what is the reality?
The start of a journey

This is the story of an ordinary South African: a man born and bred in the rural heartland of the country; someone upright and honest despite the difficulties of poverty and illiteracy. It is not only the story of his struggle with HIV and AIDS, but also the story of the attempts of his employer to help him and what was discovered on the way: the problematic relationship between the communities of public health and human rights. Even after all these years, people living with HIV and AIDS still don’t hear one united official voice speaking to them about the issues. Perhaps worst of all, many of the rights we expect from the Constitution are mere rights on paper for people who are sero-positive.

When Johannes and his employer Peter first met, neither of them could have foreseen the difficult journey down unexpected paths that they would take together. After years of seasonal farm labour and the odd piece-work, Johannes had mastered many useful skills. Now he wanted a secure job. The skills he offered were exactly those Peter needed; the two struck a deal and have worked together ever since.

Many months later Peter realised that Johannes was blind in one eye – a Christmas present courtesy of the state some years before. Years previously Johannes had saved enough money to fence off his fruit trees and inkuku. As he had worked with tensioned fencing wire it had snapped back at him, stabbing him in his left eye. Friends had commandeered a vehicle and had helped Johannes, bleeding and in great pain, to the local hospital. But the hospital staff had been unimpressed by his condition. It was Christmas Eve, they had pointed out: he should come back after the holidays and then they would see what could be done. When Johannes had returned four days later, on 27 December, his eye could not be saved. Although he lost his sight Johannes gained what he regarded as a fundamental life lesson: do not trust hospitals, doctors or nurses; the ‘government’ does not care about you or your rights.

Search for a diagnosis

Around 2005 Johannes began behaving strangely. He became obsessive and irrational. First he refused to work with other members of staff or to speak to them. Later Johannes began to threaten them and he described to Peter how he wanted to kill them. While Peter felt in no danger, others did not want to be alone with Johannes. What to do? Meetings were set up. Officials of the Department of Labour and then Social Welfare and finally the local police chief were called in to talk to him. He was
taken to several doctors specialising in family medicine. One of these doctors prescribed an anti-depressant and volunteered to Peter (who had not brought up the issue) not to worry about Johannes’s HIV status – she was certain he wasn’t HIV positive because he had “no sores in his mouth”. Eventually a black seSotho-speaking psychiatrist new to private practice was found, and Johannes had several sessions with her.

The psychiatrist found that there was indeed a serious psychiatric problem and suggested that Johannes have blood tests to find out whether an underlying physical condition could be causing it, for example a thyroid deficiency. The results, when they came back, showed the problem was more worrying than either she or Peter had imagined. Johannes’s CD4 count was very low, and the doctor urged that he should be tested to establish his HIV status.

How could Peter explain all this to Johannes? At first Johannes was furious that any blood tests at all had been carried out on him. He was also angry that the results indicated he was ill and that the cause could be HIV and AIDS. All his old mistrust of health officials – people in authority interfering with his health – surfaced again. The initial blood tests had only been carried out after a detailed explanation of the doctor’s intention and after Johannes had given his agreement, but it was thought that the tests would show whether he had some exotic hormonal problem, not that he might have the condition that no-one in his community would so much as name.

The doctor left the issue of persuasion to Peter, and it took a great deal of talking before Johannes agreed to have the test. The argument related mostly to the welfare of his children: Peter argued that if Johannes was tested and found to be positive, he could get treatment that would help him stay alive and healthy so that he could take care of them; if he didn’t test but was positive he would have no access to this medicine. And Johannes knew very well what happened to people who had ‘die siekte’ and who went untreated. He agreed, but was adamant that the testing should not be done at the local clinic. He had a point: in the local clinic setting everybody knew within minutes who presented themselves for HIV testing.

This meant finding another facility. A particular municipal clinic was identified and Johannes, accompanied by Peter, arrived early enough to be first in the queue. He asked that Peter be present for the counselling and to hear the results. This request caused some problems as the health care workers told Johannes that this was ‘wrong’: employers were not allowed to be present, they said, because...
they will sack you when they find out your HIV status. The staff seemed to interpret the right to confidentiality regarding test results in a way Peter had not come across before: they felt that an HIV-positive result was something that decent people should keep secret and not discuss with anyone else. Now Peter began to notice evidence elsewhere too that the idea of confidentiality regarding testing was sometimes confused with an obligation to remain silent.

Peter takes up the story

“They don’t know how we live,” Johannes told me later, referring to the shocked response of the health-care workers when he had insisted that I was present for the test results. “We don’t keep things secret in our house. We talk about things together.” By this he meant the place where he and I lived, and perhaps that was how he saw matters between the two of us. However, there were already secrets between Johannes and everyone else. None was to know his status: neither his two children (both under 10), nor his sister who looked after them; certainly not the estranged mother of the children, nor any member of his own extended family.

The idea of confidentiality regarding testing is sometimes confused with an obligation to remain silent.

ART and confidentiality

After the confirmation of Johannes’s positive status, we had another appointment with the psychiatrist, who explained that dementia was a well-known secondary AIDS condition. She added that she believed that Johannes’s behaviour posed a threat to himself and to others and that he should be hospitalised for observation and further assessment. This meant further delay in starting ART and anti-psychotic medication. Hospitalisation confirmed Johannes’s view of hospitals as places to be avoided at all costs; worse, during the delay his CD4 count dropped from 100 to 64.

Once Johannes was discharged it was time for us to do some serious talking. Now that his status was confirmed, what about starting treatment? I was delighted that this option was available to him. Aware of the struggle during the preceding decades to ensure that ordinary South Africans had access to ART at state expense, I saw Johannes as the beneficiary of that struggle, and perhaps even expected him to be pleased that he had a way forward. My mistake! He had no knowledge of the terrible days before ART existed and when death from AIDS was inevitable. He was also not aware of the other struggles that had put him in a position to obtain access to ART. To my chagrin, Johannes did not see any need for gratitude; not only did he assume
it was his right to get the medicine in the first place, but he was unsure whether he was prepared to take the medicine at all.

The first hurdle for Johannes was the idea that he would have to take it for the rest of his life. It took several sessions with a clinic support group before he budged on that issue. Another problem was where his ART medication should be obtained. He knew his life depended on it, he said, but he would only be prepared to start taking ART if he didn’t have to get it from the local clinic. Apparently ART was handed out there on specific days and at specific times, and so everybody in the village knew who came to collect their medicine.

A bizarre ritual began, in terms of which I collected drugs for Johannes from another centre, often making a time-consuming trip twice a month as the ART and anti-psychotic medications had fallen out of synchronicity. Attempts to maintain confidentiality involved Johannes in extraordinary efforts. When he went to visit his extended family for holidays he had to hide his tablets, gloss over his other medication-induced habits and make up stories about why he could not be away for more than a few days at a time.

Then there was the problem that state clinics were often short of the drug used to counter the serious side-effects of his prescribed anti-psychotics, including a marked Parkinsonian gait. On one occasion when the city clinic had none in stock I decided to try the local village clinic for help. They had the drug, I knew, as I had previously asked the locum pharmacist for it. On this day, however, there was someone else in charge who wanted to see Johannes’s file to check the medicine had been prescribed (even though I had an empty government medicine dispensing packet with his name and the name of the drug on it). Of course his regular village clinic file had no record of the prescription. It proved impossible to obtain the drug without going into an explanation that would disclose his condition. Now I simply buy it myself after another private doctor has written a script for us. But it could be argued that this was another case where Johannes’s rights to confidentiality were at risk.

Without help it is difficult for an illiterate person who battles even to tell the time, to manage ART. A drug in the complex prescription can sometimes change colour, shape and even strength from one month to the next. This means it is difficult to rely on appearance to determine which drug is which and what to do with it. As for taking the cocktail of ART, anti-psychotics, drugs for side-effects and medicine for any current infection or complication, the variety alone is bewildering, let alone the problems of timing each dose precisely. Perhaps the staff at the local...
clinic might have been willing to spend time explaining in detail how to take the tablets, but of course Johannes was deliberately avoiding the clinic.

The problems experienced by illiterate or poorly motivated people living with HIV/AIDS may be understood by specialist doctors at ART clinics. However, when Johannes felt too weak to work and decided that he needed to apply for a social grant, we visited a city clinic and talked to the doctor about such a certificate. “Will you continue to help him with the ARV medicines after he gets a grant and stops working?” she asked me. “Because if you can’t, he should discontinue them now. There would be no point in carrying on.”

If that remark came as a shock, far more shocking was the comment of the state psychiatrist who saw him on one occasion at the local clinic. She cautioned me about doing ‘too much’ in the situation. “He must take responsibility for his own past decisions,” she said.

The remark shook me with its implication that somehow Johannes had ‘decided’ to get infected, or that he had chosen to act in a way that he knew could result in infection. This is after all a man who cannot read and who has never been to school. He doesn’t own a television nor, until recently, did he own a radio. Just how should he have obtained his education about staying HIV negative? From his friends in the streets, people who will not so much as mention the name of the disease?

If Johannes’s constitutional rights mean anything in his local setting, I thought, surely they include the right to have a doctor treat him with respect?

Confidentiality and confusion

Johannes decided that he wanted to keep his status confidential. I honoured and supported that decision. But the issue of human rights was of great importance, and I found his position fraught with contradictions. Early this year, for example, he was bed-ridden for several weeks with a serious stomach problem. Treatment at the municipal clinic made no difference to his condition. When he saw a general practitioner in private practice it turned out that the treatment offered by the clinic was based on an incorrect diagnosis and had actually made matters worse. The particular stomach condition is relatively common among people with HIV/AIDS, according to the GP (to whom Johannes disclosed his status during their first consultation). Had Johannes continued with the regimen prescribed by the clinic, he could have become even sicker. Whose fault would that have been?
– his own for keeping silent and not giving the clinic staff all the information they needed to come to a diagnosis, or that of the clinic staff for not factoring in the possibility that it was an AIDS-related problem and reacting accordingly?

What about Johannes’s children, for whose sake he agreed first to have the test and then to take ART? They have not been tested. His sister, who cares for his children along with her own, also knows nothing of his secret. She is thus not aware that she should be particularly vigilant about their health.

The children’s mother, from whom Johannes is estranged, has also not been informed. Nor has he told his present partner, with whom he continues to have unprotected sex.

When social scientists write about the difficulty many women have in ‘negotiating safer sex’ with their partners, I previously used to imagine a macho city bouncer type, ready to beat up a woman if she so much as raised the issue of protection. Now that I must see Johannes as potentially the other partner in such an equation I have to rethink that analysis. What would be his response if a partner wanted to ‘negotiate safer sex’? What would happen if his partner raised the subject of using condoms? Might he be angry enough to threaten her, or even assault her? Having witnessed the effort Johannes has put into maintaining the confidentiality of his status, I can see that he might believe she had ‘found out’. He could fear not just that she knew but that his closely-guarded secret would be disclosed to everyone in the community. In addition, his mental instability could also be a factor in his acting violently towards a partner who raised the question of safer sex.

I mention these possibilities not to excuse violence towards women but because I have started to understand how unhelpful it would be to pass legislation requiring that someone in Johannes’s position had to inform his partner. However well intentioned such efforts by the legislature, fear cannot be legislated away.

And what of leadership? Now that he has access to a radio, Johannes has been able to listen to stories about what our political leaders say and do on the subject that affects him so deeply. What is he to make of a leader who has unprotected sex with a woman who is known to be HIV positive, and whose protection consists merely in showering afterwards? How will that affect his response when someone tries to explain to him the need to use a condom? Who in senior national leadership is actually using the words, language and concepts about HIV and AIDS that he needs to hear?
For many people living with HIV and AIDS who choose not to disclose their status, the right to privacy is tenuous indeed. The long hours spent waiting in city clinics to collect ART have made me wonder about people who rely on that source for their drugs. How do they cope if they still have a job? How many employers will allow an employee a full day off every month to collect medicine, without asking any questions? Can the employee refuse to disclose the purpose of the visit to the clinic? Would the employee have to lie?

There’s another crisis point looming for Johannes. When he applied for a social grant on the grounds of his sero-status, he gave the city address of his children and his sister. If his application is approved he will move there to live with them. But at some stage he will want to bring his family back here with him, which will mean a change in address. And once again he will be faced with the problem of how to avoid disclosure to officials he fears will breach his confidentiality. These will be local welfare staff in a community where everyone knows everyone else’s business and where even professionals are given to casual chat about their clients.

It would never occur to Johannes that he could complain to officials at the clinic about their system of allocating specific times for treating people with HIV and AIDS and handing out their medicine.

People have rights in South Africa – far more so than before 1994 – but many people in Johannes’s position are still unable to access these rights. Johannes could not challenge the grave negligence of the health authorities at the local hospital that caused him to lose sight in one eye. He had no idea that he had any legal recourse to compensation, nor would he have had any understanding of how to set about making a claim even if he had known that he had a right to do so. He therefore did nothing about a matter in which he had obvious grounds for action and in which there was no stigma and no potential loss of dignity. It is far less likely that he would ever take action if his human rights were infringed in relation to his sero-status.

Two citizens

In her book Illness as metaphor, Susan Sontag wrote

*Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only*
the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.³

At the time of writing this Review, Johannes is still alive and working for Peter. He takes his medication and gets on with his life. This is as it should be – a person living with HIV is on medication and holding down a job. But this can happen only because there is another concerned person who is able to mediate between Johannes and the public health system, a person who has power through knowledge, power through education and status, and who is articulate and ready to challenge the system. This is a person who understands the complexities of HIV and AIDS in our society and who understands that these complex issues shape and determine how people act. It is never as simple or as easy as people would have it. Taking a test and getting the result are complex and difficult. Accessing treatment and social grants is not as straightforward as the health system would have us believe. And stigma, which we believed would reduce as the epidemic became more visible, still has a powerful hold over individuals and communities.

Peter and Johannes reflect the dual citizenship of this epidemic – the healthy person with education and the potentially ill person navigating his way through the intricacies of the health system. Both are citizens of the ‘kingdom of the well and the kingdom of the sick’ – but more than that they are both also citizens of a country with one of the most severe HIV and AIDS epidemics. The severity of the epidemic should make their rights and roles as citizens even more critical and the obligations on the state to honour the rights and health of its citizens more certain.

The story of Johannes (as told by Peter) is a story of a community and a society that has muddled its way through HIV and AIDS despite national plans and many policies and protocols. It is a story where public health moves in a silent and persistent stream of conformity and regulation; a story where human rights, personal autonomy and choice are often a source of irritation to public health and to many AIDS workers in public health settings. It is a story that has its roots in the inequitable past of South Africa, in unequal social and employment relations, in unequal access to education, health care and power. It is a story that starkly highlights how in the present South Africa these complex relationships are being renegotiated, solidified and affirmed. It is a story of how even with power and a strong sense of legal capital, Peter becomes frustrated and distressed by the ways in which public health and human rights dissect and interact. And finally, it is a story of a man who has been excluded from most of the benefits of society all his life, a man aware from
his own experience and that of his family, friends and community of the force of exclusion, discrimination and brutality based on race, now facing a society where the force of exclusion, discrimination and hostility based on sero-status remains.

The purpose of this Review is to look at how HIV and AIDS intersect in our understandings of human rights and public health. These issues are not pertinent to HIV and AIDS alone but are part of how we as a society respond to many social situations where in the interests of public health, basic rights are under threat are challenged or are just ignored. The underlying debate is about why there is a tension between human rights and public health. How might these threats be addressed and challenged, and how might we strengthen the ways in which all people understand and act on their rights, and develop and understand legal capital? Finally, how might we ensure that the rights of all people are promoted and protected?
GOVERNING THE MASSES

Before the Enlightenment two basic responses dictated public health measures, these being crisis measures aimed at handling the outbreak of epidemic disease and everyday regulations dealing with civic nuisances. Italy was at the forefront of medieval epidemic control, establishing magistrates to oversee moral and physical hygiene in major cities as early as the fourteenth century. This is where the etymological origins of the term ‘quarantine’ is to be found, as it came to be used to refer to the period of forty days thought necessary to seclude the ill. Quarantine stemmed from a contagionist understanding of disease – a model based on the classification of stigmatised groups as the dangerous ‘Other.’ During this time disease causation was ascribed to ‘miasmic’ and ‘humoral’ theories, but the ultimate cause was seen to be ‘God’s will.’

During the Enlightenment people started to become critical of superstition and religion, and developed a firm belief in the ability of humanity to master its own destiny. Scientific inquiry in the form of positivism became paramount, and it was believed that laws of nature governed disease and that these could be uncovered and addressed. This led to the formation of the social hygiene movement in Europe in the eighteenth century. The Enlightenment ideal of rationalising and ordering society was responsible for the rising to prominence of the concept ‘governmentality.’ Another Enlightenment concept, the social contract, established the norm that the state would protect its citizens in exchange for the relinquishing of certain rights by the people. Medicine thus came to be not just a means of tending to the sick, but part and parcel of an administrative system and the machinery of power. As a result,

...the ‘population’ became constituted as a problem, a target for surveillance, regulation, analysis and intervention... Bodies – those of individuals and those of populations – became bearers of new
values relating to their productivity, use and general state of health. Doctors became ‘specialists of space’, posing problems to the coexistence of individuals, their density, their proximity with each other and with environmental aspects such as water, sewage, animals, the dead and housing.6

Rapid industrialisation and rampant urbanisation in early nineteenth century Britain led to the emergence of the ‘modern’ public health movement. This was a response to the many problems faced by the inhabitants of ever-expanding towns and cities. Their many concerns included dirt, sewage disposal, bad water supplies, overcrowding and poor housing. The primary concern that drove all the others, however, was endemic disease such as smallpox, typhoid, and chronic illness. The early ‘modern’ public health movement was closely allied to the ideologies of capitalism, as at the time there existed a tension between the short-term objectives of those in power and the long-term objectives of public health.7

There is an ongoing debate about the exact moment that ‘modern’ public health emerged. Some contend that public health – as distinct from somatic or individual treatment – began in 1854 when a local doctor, John Snow, helped to stem a cholera epidemic that raged in London’s Golden Square by identifying and closing an infected water pump in Broad Street.8 Others hold that ‘modern’ public health had its origins in Liverpool, the first city to appoint a medical officer of health in the 1830s. It was also in Liverpool where the first public wash-house in the world was opened in 1842, and where a local sanitary act was promulgated and passed in 1846.9 Across the Atlantic, in America, the first system of vital health statistics was put into practice in Massachusetts during the 1800s.10

During the nineteenth century, more and more governments started to regularly inspect housing conditions and rubbish heaps, and to map them in relation to the outbreaks of illness. By the end of the 1800s, governments formed boards of health to enforce sanitary regulations. States also now ever-increasingly assumed the authority to pass legislation and take coercive steps to improve the public’s health. These coercive actions included the seizure of property, the closing down of businesses, the killing of animals, involuntary testing and treatment, and – as before – quarantine. As the twentieth century rolled along, epidemiology became the science of public health, and the discipline started to be perceived being as both cost-effective and useful. Programmes based on public health discourse and practice consequently started to attract ever-increasing amounts of funding.11
Public health arose from the need to regulate the lives of citizens to curb infection and death – but what is the history of how various societies have attempted to regulate people in the interests of the general good? In the words of Peter Baldwin how are individual rights and the public good pursued simultaneously?

How does the polity treat the patient who is both citizen and a carrier of disease?

HIV and AIDS have starkly highlighted the tensions between social control and order through public health and personal autonomy. How have societies through the ages dealt with real or perceived threats from illness to the general good? Wars and panics, as well as epidemics, have all served at one time or another in history to justify significant incursions on the rights of individuals or groups.

Between 1918 and 1920, because of fears of sexually transmitted infections being passed on to soldiers and sailors conscripted to fight in World War I, the government of the United States promoted and paid for the detention of over 18,000 women suspected of prostitution. These women were held against their will in reformatories until it could be determined that they were not infectious.12 Earlier, in 1832, when cholera had struck New York City, officials rounded up alcoholics, especially poor Irishmen. In the polio epidemic of 1916 health officials routinely conducted house-to-house searches and forcibly removed and quarantined children thought to have the disease. In World War II President Roosevelt ordered the internment of more than 110,000 Americans of Japanese descent owing to an alleged threat to national security. In short it was common to violate the civil rights of the ill to protect the healthy – to abuse them in order to protect the general public.13

Traditionally, the mere invocation of an exigent circumstance has sufficed to justify acts of discrimination, with few voices raised in objection. There are many other examples given later in this discussion. AIDS seems to be sliding into this kind of circumstance.

The recent history of the world shows stark variations in the intensity of international activism concerning human rights violations. Despite rapid globalisation and expansion in the contemporary human rights movement, international attention to human rights issues remains patchy. For every voice that is amplified by transnational advocacy networks many other are ignored.14

The inconsistent response occurs despite a long history of the discourse of human rights, in that a range of very
diverse societies and civilisations have recognised the vulnerability of individual human beings and sought ways to protect them from some of the more oppressive possibilities.  

HIV and AIDS came into a world in which commitment to human rights was established by the Universal Declaration of Human Rights and a range of other treaties and covenants signed and ratified by most states. It appeared in a post-colonial world where the rights and dignity of previously oppressed and marginalised groups was recognised and protected. It came into a world in which equality between races, sexes and nations was high on the agenda.

Unlike other contagious diseases where harsh public health interventions were applied, AIDS was supposedly treated in an exceptional manner. Nevertheless it was possible to try to restrict individual’s rights in order to improve overall epidemiological security. Some saw the threat from without and imposed travel restrictions – AIDS went beyond a public health issue and beyond being a contagious disease. In attempts to curtail the epidemic’s rise – in the guise of public health – the most enduring political dilemma was how to reconcile the individual’s claim to autonomy and liberty with the community’s concern for safety. How does the polity treat a patient who is both a citizen and a carrier of disease?

AIDS then caused a deeper analysis of instincts and attitudes lying just below the surface of expressed ideology. What AIDS forced people to confront in very real terms were their own prejudices, which had previously been masked. AIDS stripped bare those who were and are homophobic, those who judge sex workers and people with alternative sexual lives, those who judge young people and how they behave. It exposed in very stark terms the extent of our prejudice and intolerance, and the depth of our social hypocrisy and dishonesty. And so it was possible to ignore the attacks on gay people, intravenous drug users and sex workers. Very soon the attacks and the distaste were not addressed to those groups but rather to the virus itself – to the extent that anyone living with the virus was shifted into a slow but consistent side-stream of society.

Should we – the question seemed to be – focus on the lives saved by traditional public health interventions, if these violate rights or focus on rights that have been violated? Tactics adopted 150 years ago to deal with cholera, leprosy and TB created a template for the responses to AIDS. Old mentalities and old ways of doing things
remained remarkably consistent. Decisions about how to treat AIDS, and the subsequent violations of rights and dignity were taken in accord with a resilient public health ideology set in place during the last century. Health is the last location for people doubtful of the value of human rights.\textsuperscript{19}

How then do we shift the terrain away from the idea that a restriction of freedoms is part of the universal good when dealing with a public health crisis?\textsuperscript{20} How do we put rights first and public health second, and how do we break the stranglehold of those who believe that in a time of crisis rights can be set aside and placed on the back-burner?

Many people have had the experience of being offered insurance that includes cover against ‘dread diseases’. The fine print tells you that this means illnesses such as cancer, heart disease, stroke and kidney failure – although not HIV, interestingly enough. These diseases are what insurers believe the rest of us currently regard as ‘dreaded’. However, society’s perception of what constitutes the most ‘dreaded’ illnesses changes over time.

Historically, as Kenneth Doka points out, dreaded diseases have been of two main types: great epidemics that cut swathes through the human landscape; and the diseases that have been – and are – feared because of their disabling, disfiguring and debilitating impact on the individuals who succumb to them. This dichotomy becomes an expression of the public versus the personal.

**PUBLIC ‘DREAD DISEASES’**

The first group of sicknesses are those that have affected enormous numbers of people over many centuries, such as the Black Death or bubonic plague, the great influenza epidemics, cholera, typhus and typhoid fever, and more recently, SARS. During these troubles, societies struggled to find an answer to why they had been visited by such scourges. Lacking a scientific explanation, the best that authorities at that time could do was to conclude that their deity was angry with the people. Usually the frightened populace or a priestly caste assumed that this anger was sparked by society’s lax morals or by heresy, and so the prescribed antidote was often atonement for sexual and religious offences. “All minorities – Jews, lepers, cripples, heretics, and homosexuals” – became suspect”.\textsuperscript{21} And so too, one should add, did many women: accused of being witches, they were often tortured until they ‘confessed’. In this way, priests (and denouncers of heretics and other sinners) came to play the equivalent role of our public health officials.
Very often, however, epidemics hit the poor hardest. The cholera epidemics in the United States during the early 1800s are an important illustration because of the fault lines they exposed in that society, highlighting strong prejudices against the poor and those regarded as ‘other’. At the time, cholera was seem as “a demonic, evil and foreign force” similar to, if not worse than, smallpox or the plague.22

Despite the known pedigree of cholera as a not particularly selective killer, when it arrived in the United States during the early 1800s, it was immediately associated with poverty-stricken Irish immigrants fleeing famine. “As the newest and the poorest immigrants, the Irish lived in the worst housing, under the most crowded circumstances, and were least able to afford good water, medical care, or flight from the epidemic”.23

But not only were the poor and destitute worst hit by the disease, they were also blamed for its very existence. In turn they suspected they were being deliberately targeted as its victims. “[I]t fanned class resentments and hatred. As with HIV, many of those infected with the disease, or at least those at risk, suspected the authorities of either developing the disease or facilitating its spread”.24 In the United States, the disease encouraged further anti-Catholic and anti-immigrant bigotry as the first mass migration of Irish Catholics had seemingly been immune to cholera. The disease also worsened class conflicts.

According to Professor Kenneth T. Jackson, professor of history at Columbia University, the initial response to the epidemic exposed more than ever the city’s divisions of class, race and religion. “The disease hit hardest in the poorest neighbourhoods, particularly the slum known as Five Points, where African-Americans and immigrant Irish Catholics were crowded in squalor and stench”.25

And yet everyone was at risk, as those who could afford it fled the already infected towns and villages, taking the disease with them and infecting populations in other areas.

In response to the epidemic, officials planned to quarantine ships and other cross-border transport that could facilitate the spread of the disease. This angered the wealthy whose interests were thus put directly at risk, and their reaction was to deny the existence of the disease.26 Official cordons tried to reduce the mobility of those who might spread the disease, and though these were much resented by the poor (who felt they were being imprisoned in their slums) as well as the rich (who feared the impact on trade and resented any suggestion that they might be implicated in the ‘poor man’s plague’), the new powers and regulations in terms of
which the cordons were proclaimed “signalled the beginnings of public health”.27

In every part of the world where ‘public health’ was promoted, it used coercive means to control highly contagious diseases. Although municipal and city officials attempted to combat disease using improved sanitation, this did not prevent the continuation of old responses to epidemics such as scapegoating.

The influenza epidemic of 1918-1919, almost a century after the cholera outbreaks, was blamed by many in the USA on the Axis powers, especially Germany, then at war with the Allied powers. “The assumption was (despite the fact that Germans were dying from the disease) that the Germans directly caused this plague, releasing infection from U-boats and spoiled medicines and indirectly as a result of poison gas. The suspicions and rumours were such that the US Public Health Service was forced to test the purity of Bayer aspirins, because the company had German roots”.28

Even today, scapegoating continues to be a public response to contagious illness. The social tensions caused by epidemics also tend also to spur race conflict, as ‘others’ believed to be in some way responsible for widespread illness in a community are often of a different race.

This phenomenon was seen again in the United States in the early 1900s, when bubonic plague broke out in some areas, revealing different fault lines in that society. This time, the ‘others’ were Chinese. An article in The Washington Post of 1 February 1900 reported:

In an effort to stamp out the plague, it was decided to burn one of the blocks in Chinatown [in Honolulu, Hawaii]. The fire was started and it gained such a head way that the fire department could not control it. The flames spread rapidly from one block to another and soon the whole Chinese quarter was in flames. Hardly a house was left standing; 4 500 people were rendered homeless and they are now living in tents.29

White residents and officials of San Francisco also targeted Chinese residents of that city when the plague, brought by rats on ships crossing the Pacific, landed in San Francisco and infected the local rodent population.

After the turn of the century, discrimination against Chinese Americans culminated in two acts, the quarantine of San Francisco’s Chinatown, and indefinite extension of the Chinese Exclusion Act of 1882. The reason San Francisco’s Chinatown was quarantined was that the dead body of a Chinese labourer was found, and it was suspected that he
had died of bubonic plague. While the cause of death had still not been determined, a cordon was placed around Chinatown, and no Chinese American was allowed to leave the area bounded by California, Kearny, Broadway, and Stockton Streets. This restricted the freedom of movement of people ... It caused them many hardships, for they had difficulty in obtaining goods and services from people outside Chinatown ... Finally, after three and a half months, it was found that there were no cases of bubonic plague within Chinatown. This lengthy quarantine of Chinatown was motivated more by racist images of Chinese as carriers of disease than by actual evidence of the presence of bubonic plague.  

According to San Francisco’s Department of Health there were many ways in which a second plague outbreak, after the great earthquake of 1906, was treated differently. The city health authorities instituted a massive clean-up that included pouring concrete flooring in barns and stables, and mounting a project to eliminate rats, in which everyone was encouraged to become involved. The new policies were born of a new scientific understanding about plague. Most importantly, policies were broadly applied and depended upon the participation of everyone in the city.

There was another serious spin-off of the racist handling of the first plague outbreak. The Chinese community in San Francisco developed intense suspicion of public health officials. Tension was so great that the city stopped providing health services in Chinatown from the time of the plague onwards. Although the tuberculosis death rate in the Chinatown district was six times higher than in the rest of the city, no provisions were made for TB clinics in the district until 1933.

In the poor handling of the 1900 outbreak of plague in San Francisco’s Chinatown, we can see the disastrous short-term and long-term results of a public health policy unmediated by concerns for the rights of a community. The racism of the authorities at that time is obvious to us today. Yet even today in South Africa the guaranteed rights to health of certain groups – including prisoners with HIV, foreigners and child-headed households – are neglected by those who should be most careful to protect them.

Quarantine is a centuries-old practice, dating back to the medieval plagues, when ships were held in Italian ports, and could not be offloaded for 40 days. These practices were not based on any real understanding of how epidemics spread or of the causes of any particular disease. Rather, Doka suggests, they were an expression of panic.
“They were a ritual cleansing of the community, isolating those who had the disease.” Inevitably these practices affected the rights of the individuals concerned, and tension arose between the larger group that invoked the right to protect themselves, and the group targeted to give up some rights. Support for quarantine was the basis for the response to HIV/AIDS in Cuba, where people with HIV were put into quarantine.

Decisions about whose rights should take precedence will sometimes be made by health officials on the basis of what action appears easiest to institute. Often such a decision is made by health officials who are unquestioning members of the group in power. The outcome of such a situation can be a decision or policy which is based on unexamined prejudice against the rights and interests of the poor and the less powerful.

This is another reason to promote the inter-connectedness of human rights and public health, for it is the particular strength of a human rights approach that it will discover hidden prejudices, stereotypes and scapegoats.

PERSONAL ‘DREAD DISEASES’

There is a second category of ‘dread disease’. These are sicknesses that cause enormous fear not because of their ability to infect enormous numbers of people (as with the plague), but rather because individuals who become infected are seen as undergoing a slow, tortuous, disfiguring, shameful death. The cause of fear might thus be that the nature of the illness itself brings stigma and shame to the individual affected.

These diseases have one feature in common with the great plagues. Just as those who succumbed to cholera in the 1830s were blamed for an inherent moral or spiritual weakness that left them easy prey to the disease, so those who become infected with these shameful individual illnesses are also frequently blamed. One of the most stigmatised diseases is leprosy or Hansen’s disease. In the past, those who had contracted this disease were shunned by the community, and were thrown out to live on their own far from the rest of society. Yet in fact the disease, at least as we now know it, is only mildly contagious and difficult to transmit.

Given how rare it is today, and our understanding of the difficulties of transmission, it is ironic that the disease has left such a legacy in our communal psyche. Although the
disease may no longer generate the same fear as in the past, it “is still a metaphor of loathsomeness for all the diseases we now label the leprosies of our time”.  

Another disease that provokes stigma and shame is syphilis, given its association with promiscuity, and symptoms that include ulcers, blindness, insanity and paralysis. “Many of the debates that currently surround HIV – confidentiality, contact tracing, premarital or mandatory testing – had their origins in debates about syphilis. Similar fears were evident – that casual contact, even drinking from a common cup, could spread the disease or that it was deliberately spread by some of those infected. Indeed, syphilis becomes the first disease that creates a conflict between morality and secular rationalism that would bedevil treatment. In the end it was penicillin that removed the sense of dread”.  

Tuberculosis came to be associated with poverty, and for the middle classes it was a mark of shame to admit to suffering from it.

Throughout much of history tuberculosis was a major cause of death and regarded as another of the great pestilences. It was called the White Death and the White Plague, and evidence of its power to kill can be found as far back as 5000 BC. Tuberculosis emerged with new power and visibility in the nineteenth century. The marked changes in the way people lived in Europe as a result of the industrial revolution created conditions that permitted it to spread more efficiently. “The tuberculosis bacilli can survive in the droplets of cough for hours, lingering in the air. Overcrowded factories, tenements and cities offered an ideal environment for the spread that was lacking in a more rural agrarian society”.  

Like AIDS, tuberculosis produced tremendous fear. It was unpredictable, for although the bacterium usually affected the lungs, it could affect any organ, producing diverse symptoms ... Its early symptoms (fever, weight loss, fatigue, a dry cough) were indistinct, mimicking many common conditions ...

Every third person between the ages of 15 and 60 in the country – or about one in ten – died of TB. It was a wasting disease that was also highly contagious, which meant that sufferers were usually ostracized.  

Tuberculosis came to be associated with poverty, and for the middle classes it was a mark of shame to admit to suffering from it. Doctors tended to not ascribe the cause of death on death certificates to tuberculosis, apparently out of concern that survivors would be embarrassed or further stigmatised.

In both the grand epidemics of the plague and in individual diseases characterized by shame and stigma, it took only a small step to blame the victims for their illnesses. They
could be accused of spreading the disease, or they could be blamed for contracting the disease in the first place. Claims that those who had the disease deserved it served two functions. It gave meaning to the event. “An incomprehensible horror becomes understandable.” And it was also protective. “The thought that only those who deserved the disease received it, alleviated anxiety. If one lived right or prayed right, one was protected from illness”.36

Is HIV and AIDS both a public and a personal ‘dreaded disease’?

In a sense, HIV/AIDS has emerged as the archetype of a dreaded disease, combining the factors that had made other illnesses so feared. It has elements of the great plagues – it affects huge numbers of people and has a high mortality rate. But it also represents much of what made individual illnesses so feared – it is disfiguring, debilitating, and is associated with shame and stigma. The cause of the shame and stigma is the association between HIV and “sex, sin, deviance and death”.37

Privately experienced illness became not only a public phenomenon but also, as political actors slowly agreed that it demanded a public response, a public problem. More than two decades after it was first diagnosed, AIDS is one of the leading political and social dilemmas facing all societies in the world.38

Some on the religious right have seen AIDS as a kind of “divine retribution” for an immoral life.39 Many have regarded people with HIV as “identified with socially defined deviant groups such as homosexuals or drug addicts ... Hence the disease carries a strong moral connotation in which victims are blamed for their fate”.40

One should hardly be surprised that many choose to view AIDS metaphorically plague-like, as a moral judgement on society. Public figures can’t resist the opportunity offered by a sexually transmitted disease that kills. Thus, the fact that AIDS is predominantly a heterosexually transmitted illness in the countries where it first emerged in epidemic form has not prevented such guardians of public morals as Jesse Helms “from depicting it as a visitation specially aimed at (and deservedly incurred by) Western homosexuals, while Jerry Falwell offers the generic diagnosis that ‘AIDS is God’s judgment on a society that does not live by His rules’”.41

What this brief look at some examples of past epidemics and dread diseases illustrates is the need for public health and human rights to form a powerful partnership (in opposition to ignorance and prejudice). Such partnerships
may alleviate the suffering of people who need to access health care, and see to it that sound health policies are devised, respected and implemented. Such alliances may contribute to a culture respectful of everyone’s rights and in this way help build a society in which we all enjoy the highest attainable standard of health.

The chapters that follow look in detail at how and where public health and human rights should be able to forge tight alliances and collaborate in the interests of securing public health and ensuring personal health care, rights and dignity. The importance of protecting human rights which are starkly highlighted by the responses to HIV and AIDS is the focus of the next chapter.
Chapter two:
Public health and human rights

The idea that human rights and public health must inevitably conflict is increasingly tempered with awareness of their complementarity.42
– Gostin & Mann

With the formation of the United Nations in 1945 and the Universal Declaration of Human Rights in 1948, the links between attaining the right to health, health care and human rights became increasingly understood.

The basic characteristics of human rights are that they are the rights of individuals, they apply to people everywhere in the world and they are generally about the relationship between individuals and the state. They are about what governments can and cannot do to their citizens, and what governments should do for all their citizens.

The right to health embodied in various treaties requires that states act to ensure that all citizens have the right to health and to other social benefits such as food, shelter, education that will impact on their health. In many cases, however, protecting the rights of people who are not ill or who do not have some infectious disease is often seen as being of greater worth and value than ensuring that people who are ill or who do suffer from an infectious disease are protected by the state and their human rights realised. Actual linkages between health and human rights are relatively recent and have increasingly become the focus of debate and policy developments.

Healthy bodies, healthy state

By way of genealogical analysis,43 Michel Foucault and others have shown that the institutions of medicine and public health have been crucial in establishing the ‘normalizing gaze’ as part of mass observation and social regulation.44 For centuries public health discourse and practice, in all their numerous incarnations, have been ways of constructing and regulating the bodies of the individuals that comprise societies.45 Seen in this way, public health is not merely “the societal approach
to protecting and promoting health”\textsuperscript{46} that has as its aim to improve the well-being of communities through social actions, but an authoritative and therefore socially determinant discourse – infused with power – about how societies should be ordered. The tools with which these discourses are constructed include the creation and enforcement of health-related legislation and regulations such as sanctioning screening, treatment, immunization, and even quarantine.\textsuperscript{47} The latter – a characteristic facet of responses to epidemic threats since the late middle-ages – is so permeated with stigmatization that it has come to represent “far more than the mere marking off or creation of a boundary to ward off a feared biological contaminant lest it penetrate a healthy population... When an epidemic illness hits hardest at the lowest social classes or other fringe groups, it provides that grain of sand on which the pearl of moralism can form.”\textsuperscript{48} This illustrates clearly the power of public health discourse in the construction of hegemony, and the extent to which governments can ‘legitimately’ regulate the lives of their subjects in order to protect and promote the health of citizens’ bodies and of the body politic.

Some people believe that the medical and public health professionals have too much power and too high a social status and that society has become too reliant on them and the services that they offer. There is an increasing tendency of the public health system to provide the answers to social as well as medical problems. Sometimes the health professionals are regarded as having too much power and controlling or oppressing their patients, but access to good medical care is regarded as the right of every person. Medical views on health, illness, disease and the body dominate public and private discussions.\textsuperscript{49}

In many of the public health issues medical professionals see only the patient/body that has some illness or fear of illness. They tend to believe that individuals can alter and change their behaviour on the basis of ‘good advice’ or information. Seldom is the whole world view of the patient/body fully understood and that people may not be able to exercise choice, determine their behaviour or even act on the information. Seldom is it understood that patients/bodies may not want to act on this information – such as testing or going onto treatments or being circumcised.

Lupton\textsuperscript{50} (quoting Frank) suggests that there are four ways of looking at bodies in medicine – the medicalised body; the sexual body; the disciplined body and the talking body. While the distinctions between these are
fluid the medicalised body is most directly related to medical management of disease, the sexual body has become – especially with HIV and AIDS – drawn into and is disciplined by the medical discourse, the disciplined body is also part of discussion about control and health while the talking body is expected to be able to talk to the public health professionals about symptoms, disease and behaviour.51

This mirrors Foucault’s view of medicine as a major institution of power in labelling bodies as deviant or normal, as hygienic or unhygienic, as uncontrolled or in need of control.52

These views of the body have taken on a powerful symbolism in the HIV and AIDS epidemic, with public health interventions that place education and prevention back in clinic settings and under the public health agenda. Such interventions are developed and discussed with scant attention to the social and political issues that determine and confront people’s lives, indeed the public health discourse is impatient with social science and social theory, and impatient with attempts to situate public health interventions within a wider framework of critical engagement with the lives of the people for whom these interventions are being designed. There is also an irritation with rights and the protection of individual rights which are seen to interfere with the work of health professionals. There is also a lack of accountability for social events that happen as a consequence of such public health interventions.53

The public health approach was strengthened by the WHO Global Strategy for Health for All by the Year 2000. The aim of this strategy was to ensure that “all people in all countries should have at least such a level of health that they are working productively and of participating actively in the social life of the community in which they live.”54 This goal was to be achieved by the promotion of life styles conducive to health, the prevention of preventable conditions, and rehabilitation and health services. Increasingly the role of public health in the social and political lives of citizens is being increased and strengthened. An idea supported by the views of many is that the high level of public health is important for the smooth running of society and that people must “fit in” to this world view. The key ideal is the elimination of health inequalities and a strengthening of the public part of public health. Now more than ever citizens were required to make sure that they were responsible for attaining good health with the emphasis on individual behaviours – the disciplined body! WHO has continued to have a defining role in how public health interventions are conceived and developed and to define the ways in which illness and
health are viewed as part of the political process and governance.

**BODIES HAVE RIGHTS**

The tension between the public health ‘position’ and the human rights ‘position’ lies in the belief that in a human rights approach individual rights are protected at all costs, even if this leads to adverse affects on the public’s health. Many public health practitioners believe that a rights-based approach privileges the protection of the individual’s rights over the public good. They argue that at times for good ‘public health’ it is necessary to restrict individual rights – particularly if exercising these rights would place society at risk. This view has its basis in how public health measures have dealt with pandemics in the past. In public health responses to communicable diseases (such as the influenza epidemics in the past and, indeed, SARS in the present) the traditional tools of compulsion, coercion and restriction have been applied almost unchallenged. With HIV and AIDS this public health approach had to be revised in the light of human rights. The new norms would include confidentiality, testing only after counselling and informed consent, and the safeguarding of human rights. Such public health interventions only apply when the disease of concern has carriers who are contagious. Contagious diseases transmit through common social contacts, whereas sexually transmittable diseases (including HIV) are communicable but not contagious. There is a major difference in terms of public health challenges between an epidemic such as influenza or SARS, and HIV and AIDS. They seem to represent the polar ends of a spectrum of complexity in terms of tactics of public health. HIV and AIDS is a prolonged epidemic, infection is surreptitious, infected persons harbour the virus for life, the incubation period is measured in months – but it is non-contagious. Targeting people with HIV using public health measures – appropriate for contagious diseases – is unscientific, discriminatory and violates human rights.55

One of the reasons most often advanced to justify the erosion of human rights in public health responses is that there is not enough time to deal with human rights issues in the face of an emergency that requires exceptional steps. This reasoning is flawed on two counts.56 First there seems to be a perception that the protection of human rights requires too much time. Second, there is an implicit assumption that avoiding the protection of human rights will mean being able to control and reverse the epidemic.
However, the solution to the AIDS crisis is not as simple as testing every person and disclosing their status publicly. It is a highly complex crisis that requires deep-rooted and long-term changes such as gender equality, institutional capacity and resources, and a serious response to poverty.57

The Universal Declaration of Human Rights consists of two parts. The first 21 articles deal with civil and political rights, while the remaining 9 articles are about economic and social rights. Human rights experts concur about how to protest violations of the first set of rights, but argue about the second set, and about how they are protected or threatened by traditional public health approaches.

These two sets of rights were generally thought to be fundamentally antagonistic and had, until very recently, evolved along parallel but distinctly separate tracks. According to Gruskin and Tarantola,58 a number of recent events helped to bring them together. These events include the HIV and AIDS pandemic.

Human rights need to be both promoted and protected.59 The promotion of human rights is achieved through developing awareness, setting standards and interpretations, and the creation of national institutions. Awareness of human rights is a precondition to acting on them and is developed through human rights education and awareness campaigns. In support of this the UN declared a ‘decade of action’ for the period 1995-2004. The protection of human rights involves a complex web of national and international mechanisms to monitor, judge, denounce and coerce states to act, as well as providing support and redress to people whose rights are threatened or violated.60

BRINGING ABOUT CHANGE

One of the great advocates of public health and human rights, Jonathan Mann, said that health and human rights have rarely been linked in an explicit manner. But, he argued, “health and human rights are both powerful, modern approaches to defining and advancing human well-being”. In his view, there would be many advantages to a “meaningful dialogue” between the two.

The question as to what human rights and public health have to say to each other may be reasonable in itself. However, the fact that the question is still widely asked in South Africa at the start of the 21st century indicates that something is amiss. If the same question had been asked 150 years ago, it would have been a lot more understandable.
Societies then took whatever action they felt necessary to protect themselves against the sick. No-one thought about the ‘rights’ of the contagious sick, or those thought to be contagious and sick. Knowledge of the causes of illness was still limited.

Although we now have the scientific knowledge necessary to understand illnesses better, at the level of public health we are still sometimes badly wrong about prevention. Decisions about public health continue to be made on the basis of poor data on transmission and treatment, as shown by the way that many governments have responded to HIV and AIDS, demanding that people with HIV are treated in a manner that both undermines their human rights and that does nothing to prevent transmission.

Australian Judge Michael Kirby speaks about Dr June Osborn, who was professor of public health at the University of Michigan,

From the start, Professor Osborn insisted that WHO, in all of its interventions on HIV/AIDS, should rest its strategies on the best available empirical data ... AIDS was such an emotional, frightening and stigma-laden condition that nothing else would suffice. In the place of ignorance, superstition, moralising and fear would be substituted good science, empirical data and a sound knowledge of the epidemic and its modes of transmission.

This was the first real blow for respect for human dignity in the global struggle against HIV/AIDS. WHO would insist, from the outset, upon an empirical approach. It would oppose the extreme and disproportionate reactions of those who demanded quarantine or other protections excessive to the condition and irrelevant to the modes by which HIV was transmitted from one person to another. Epidemiology is, however, particularly well suited to explore, portray and explain new medical phenomena. It seeks to measure and analyse the occurrence and distribution of diseases and other health-related conditions in human populations, acting both as a sentinel who warns of shifts in disease patterns and as a scout who seizes on such shifts to discover their etiology.

This then, is one of the key elements in any linkage: the value of a proper human rights input on health questions is that it can help ensure that decisions are based on fairness, science and fact, rather than on fear, prejudice or ignorance.
A human rights approach mandates that any public health strategy, whether or not rights are to be restricted, be informed by evidence and openly debated.\textsuperscript{63} This approach protects against unproved and potentially counter-productive strategies, even those motivated by genuine despair in the face of overwhelming public health challenges. A rights-based approach does not privilege protection of individual rights over the public good. The introduction of human rights into public health is not about the imposition of any preordained result but about processes and their application towards maximum public health gains.

If this seemingly good result with its win-win outcome can flow from interaction between the two, why has this kind of intersection and linkage been so slow to get off the ground?

The WHO suggests that health is “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”. The preamble to the WHO Constitution declared that “the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being.” Thus defined, health is no longer purely the domain of the doctor, the clinic and the medical laboratory. “[B]y explicitly including the mental and social dimensions of well-being, the WHO radically expanded the scope of health and, by extension, the roles and responsibilities of health professionals and their relationship to the larger society”.\textsuperscript{64}

When health and human rights work together, human well-being could be more effectively achieved than if either discipline worked in isolation.

Gostin and Mann investigate three ways in which health and human rights are linked: (i) the impact of health policies and programmes on human rights; (ii) human rights violations and their impact on public health and well-being; and (iii) human rights and public health, and the promotion and protection of both.

Every major government, medical, public health and legal organisation which has issued a report on the HIV epidemic has condemned discrimination because it violates basic tenets of individual justice and is detrimental to public health.\textsuperscript{65}

Mann’s call was for greater attention to be paid to the rapidly evolving relationships among medicine, public health, ethics and human rights in response to an emergent global health crisis. His vision was to promote human rights as a corrective to bioethic’s focus on individualistic issues and autonomy, to the exclusion of social and political determinants of health.\textsuperscript{66}
Health challenges facing the global poor are daunting, and include infectious disease pandemics (such as HIV/AIDS, TB and malaria), and limited access to adequate health care facilities, goods and services (including a dearth of medicines and health care workers). With the initial responses to HIV and AIDS seemingly conforming to traditional public health measures, Mann stressed the need to ensure that HIV and AIDS responses were firmly placed in a human rights framework – not only to protect people living with HIV and AIDS but to recognise as well, how other rights violations made people more vulnerable to possible HIV infection, stigma, prejudice and discrimination. He was praised in this by the current head of UNAIDS, Peter Piot, who declared: “The world’s approach to combating AIDS would surely have been very different; [it] would have had much less to do with human rights issues and might very well have gone towards quarantine”.  

HOW HEALTH POLICIES AND PROGRAMMES IMPACT ON HUMAN RIGHTS

Inherent in all three of these functions are points at which human rights could either be improved – or worsened. When the state assesses health needs and problems for example, it prioritises some needs and health problems over others. When the needs that are ignored are those of groups that are already marginalised or stigmatised, such as sex workers or people with HIV, this negatively impacts on the rights of groups which already struggle to have their rights acknowledged.

Once needs have been assessed and the necessary data has been obtained, a state must set about formulating policies to deal with the problems it has identified, through prevention and control. Here again there are opportunities to enhance or further detract from human rights. Right from the start there can be infringements of rights if the state acts without proper transparency – if the public is not informed about or able to be involved in debate for example, or if the government will not engage with the public about the scientific underpinnings of its policies. It may also turn out that the priorities chosen by the government ignore a major health problem of a particular group: that group’s rights not to be unfairly discriminated against could then be put at risk.
Once the state has the data and policies it needs, it must ensure that the health services needed by people are in fact available. Again it is important to look at the resulting provision of services through human rights spectacles: if the health care that is provided for a particular community is too expensive for anyone to access, then the right of that group to health care cannot be said to have been met – for example, if a women’s clinic is provided in an area that is known to be dangerous for women to walk through. As Gostin and Mann put it, “[D]etails such as hours of service, accessibility via public transportation and availability of day care may strongly and adversely influence service utilisation”.70

Public health has a long tradition, anchored in the history of infectious disease control, of limiting the ‘rights of the few’ for the ‘good of the many’. Thus coercive measures such as mandatory testing and treatment, quarantine and isolation are considered basic measures of traditional communicable disease control.

The principle that certain rights must be restricted in order to protect the community is explicitly recognised in the International Bill of Human Rights … However, the permissible restriction of rights is bound in several ways. First, certain rights (e.g. the right to life, right to be free from torture) are considered inviolable under any circumstances. Restriction of other rights must be: in the interests of a legitimate objective; determined by law; imposed in the least intrusive means possible; not imposed arbitrarily; and strictly necessary in a “democratic society” to achieve its purposes.71

Human rights do not conflict with such restrictions, so long as the objectives and process used to make the decision to restrict rights are clear. For a restriction to be considered legitimate, a government has to address five criteria which have been spelled out in the Siracusa Principles72 adopted by the UN Economic and Social Council.

These five criteria are:

- first, the proposed restriction has to be provided for and implemented in accordance with the law
- second, the restriction has to be directed towards a legitimate objective of general interest, such as preventing further transmission of HIV
- third, it must be strictly necessary to achieve the objective in question
- fourth, no less intrusive and restrictive means should be available to meet this objective, and
- fifth, it cannot be unreasonable or discriminatory in its application.
The burden of proof falls on those who want to restrict rights, and concrete public health evidence is needed to respond genuinely to the last three criteria.

HOW HUMAN RIGHTS VIOLATIONS IMPACT ON PUBLIC HEALTH

The most obvious illustration of human rights violations’ impact on health is that of torture and other practices regarded as ‘severe’ violations, such as extra-judicial executions. In cases like these health officials very often use their skills to help human rights experts in documenting the abuses and investigating exactly what happened (particularly when those who might have been able to give evidence are dead). Such assistance was seen in South Africa during the apartheid period when associations of doctors made their expertise available to examine detainees and others whose human rights had been violated by the government through torture.

But, as Mann et al. point out, the impact of human rights violations on health goes far beyond these kinds of issues. A more complete understanding of the negative health effects of torture must also include its broad influence on mental and social well-being; torture is often used as a political tool to discourage people from meaningful participation in or resistance to government. Second, and beyond these serious problems, it is increasingly evident that violations of many more, if not all human rights, have negative effects on health ... Other violations of the right to information, with substantial health impacts, include governmental withholding of valid scientific health information about contraception or measures (e.g. condoms) to prevent infection with a fatal virus (HIV).

To focus only on the socio-economic status of a particular group as its ‘essential condition’ for good health has considerable drawbacks. For example, health workers are not trained to deal with this challenge (i.e. overcoming the limitations set by poverty) and may well become apathetic because they see themselves as unable to act. However, additional ideas have been proposed about the ‘essential conditions’ for health, such as those embodied in the 1986 Ottawa Charter for Health Promotion: “the fundamental conditions and resources for health are peace, shelter, education, food, income, a stable eco-system, sustainable resources, social justice and equity”.

THE LINKAGE BETWEEN HUMAN RIGHTS AND HEALTH
As the HIV epidemic has developed, a rights analysis has emerged and appears increasingly appropriate. Mann suggests: “Women’s vulnerability to HIV is now recognised to be integrally connected with discrimination and unequal rights, involving property, marriage, divorce and inheritance. The success of condom promotion for HIV prevention in this population is inherently limited in the absence of legal and societal changes which, by promoting and protecting women’s rights, would strengthen their ability to negotiate sexual practice and protect themselves from HIV infection”.74

... HIV/AIDS may be illustrative of a more general phenomenon in which individual and population vulnerability to disease, disability, and premature death is linked to the status of respect for human rights and dignity.75

From the perspective of human rights, health experts and expertise may contribute usefully to societal recognition of the benefits and costs associated with realising or failing to respect, human rights and dignity. This can be accomplished without seeking to justify human rights and dignity on health grounds (or for any pragmatic purposes) ... Finally the importance of health as a precondition for the capacity to realise and enjoy human rights and dignity must be appreciated. For example, poor nutritional status of children can contribute subtly yet importantly to limiting realisation of the right to education; in general, people who are healthy may be best equipped to participate fully and benefit optimally from the protections and opportunities inherent in the International Bill of Human Rights.76

The potential for linkage and collaboration benefits between health and human rights is only now being seriously explored. But it is already re-shaping both fields individually, broadening the points of intersection and building new ways of advancing human wellbeing.

It may be useful to adopt the maxim that health policies and programmes should be considered discriminatory and burdensome on human rights until proven otherwise.77

Gostin and Mann suggest that a tension between health and human rights may be good and that the human rights community should approach existing and proposed health policies (that have not already been tested for rights’ conformity) on the basis that they will probably be “discriminatory and burdensome on human rights”. Gostin and Mann explain that this is because public
health policies are sometimes formulated “without careful consideration of the goals of the policy, whether the means adopted will achieve those goals, and whether intended health benefits outweigh financial and human rights burdens.”

Few public health officials know about human rights, and fewer still have the skills to assess policies from a human rights perspective. Equally problematic is that human rights activists are seldom active in public health.

**SEVEN STEPS FORWARD**

A seven-step plan, adapted from Gostin and Mann, is described below in the hope that it could prove helpful in balancing the benefits of a public health policy against human rights concerns. The objective is to carry out a human rights impact assessment of any public health policy.78

**Preliminary stage: Fact-finding**

Rigorous and impartial fact-finding involves gathering of relevant information from various disciplines, including for example, virology and social services.

Institutions that seek to justify public health strategies (such as ministries of health, environment or justice) may present seemingly credible arguments based on ‘hard evidence’. However a proper set of ‘facts’ presented by the government may be incomplete or biased. Proper fact-finding requires broad-based consultation with international agencies, non-profit organisations, public health or other professional associations, community-based or advocacy groups, and community leaders, who can provide invaluable perspective regarding how health policies affect human rights in their communities. Discussions with individuals affected by the policy, and their advocates, are particularly important. When consulting these sources, special efforts should be made to gather material representing all viewpoints, to ensure a balanced picture.79

**Step one: Clarify the public health purpose**

A clear understanding of the public health purpose to be achieved is essential. Government has a responsibility to articulate this public health purpose ... A precise conceptualisation of purpose will more likely lead to sound, properly conceived
policies. Examples of narrowly defined public health goals include ... prevention of tuberculosis transmission (by assuring compliance with treatment through directly monitored therapy).°

Clearly articulated goals help to identify the true purpose of the intervention, facilitate public understanding and debate around legitimate health purposes, and reveal prejudice, stereotypical attitudes, or irrational fear.°

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Step two: Evaluate likely policy effectiveness

Existence of a valid public health objective does not justify a policy. Public officials need to show that the means used are reasonably likely to achieve the stated purpose.

This step requires an honest, rigorous investigation of a policy’s potential effectiveness and would involve consultation with the affected groups as well as examining the facts and expert opinion. Even in an emergency, decisions must be based on rigorous assessment of the available data.

Some questions that would be appropriate for this stage of the assessment include the following:

- If it involves a test, such as screening for HIV, is the proposed testing programme appropriate and accurate?
- Is the intervention likely to be effective? If the programme does not include provision for good follow-up capability, like education, counselling or treatment, then although cases of infection may have been identified the intervention will still not have been effective.
- Is there a better approach? The answer to this might be found by comparing the proposed policy with alternatives.

Sound public health policies must avoid both under- and over-inclusiveness. A policy is under-inclusive when it reaches some, but not all, of the persons it ought to reach. Certain under-inclusive policies may mask discrimination – such as when a government uses coercive powers to target politically powerless and vulnerable groups, but not target others that engage in similar behaviour. The government is not obliged to devise policies that address the entire population with the potential to transmit disease. It may, instead, choose to address a public health problem one step at a time. However, “if the sub-population targeted for coercion or punishment is chosen for reasons not directly related to public health, the under-inclusion is impermissible”.

Step three: Determine whether the proposed public health policy is well-targeted

Ideally, public health strategies should be tailored for those who will benefit from them. Thus, every policy creates a class of people to whom the policy applies and a class to whom it does not. A policy that appears neutral may in fact disproportionately impact on certain groups in society.

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Over-inclusiveness occurs when a policy extends to more people than necessary to achieve its objective. Over-inclusiveness may not be cost-effective, as when
counselling all persons entering acute-care hospitals about HIV infection. However, over-inclusiveness with regard to a coercive power is almost always unacceptable. Compulsory measures (against HIV transmission) that apply to all homosexuals, commercial sex workers, intravenous drug users, or foreigners from countries with high rates of HIV stem from the erroneous belief that all members of the group will engage in unprotected sex or needle-sharing.84

“These rights must never be infringed, even if the country is in a declared state of public emergency and the public health need is extraordinarily strong. Non-derogable rights include freedom from discrimination; the right to life; freedom from torture and from cruel, inhuman, or degrading treatment or punishment; freedom from slavery or involuntary servitude”.

Other rights may be restricted in certain situations, but generally they must be prescribed by law in a democratic society and the restrictions must be necessary to protect a valued social good (in other words there must be a compelling public interest at stake). Restricting human rights should never be taken lightly.

Minor infringements on human rights may be justified when the public health interest is compelling and there is no other way to achieve the objective. For example, requiring the immunisation of a population by means of a safe and effective vaccine may undermine the right to security of person, but the substantial reduction in morbidity and morality may justify the intervention.86

How can a human rights burden created by a public health policy be measured? Four factors may be considered: (1) the nature of the human right, (2)

Step four: Examine each policy for possible human rights burdens

A human rights impact assessment involves a meticulous balancing of the potential benefits to the health of the community with the human rights repercussions of the policy.

The International Bill of Human Rights may be considered the source of basic human rights. In South Africa the Constitution and the Bill of Rights contained in it must be the first standard for any proposed health policy to satisfy.

Certain human rights are so essential to the dignity and well-being of people that they are considered absolute.

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the invasiveness of the intervention, (3) the frequency and scope of the infringement, and (4) its duration.\textsuperscript{87}

Finally, public health programmes should incorporate the principle of informed consent. This doctrine is most clearly applicable to biomedical research, but may also include other health programmes such as testing and treatment. “Consent should be viewed as more of a process of communication and interaction with the patient than a stark legal requirement”.\textsuperscript{88}

**Step five: Determine whether the policy is the least restrictive alternative that can achieve the public health objective**

The principle of the least restrictive alternative seeks the policy that is least intrusive while achieving the public health objective as well as, or better than the policy under consideration.

To determine the least restrictive alternative, non-coercive approaches should first be considered. If non-coercive approaches are insufficient, gradual exploration of more intrusive measures is permissible where clearly necessary.\textsuperscript{89}

Governments sometimes feel public pressure to respond to an urgent public health concern with restrictive or punitive measures. For example, public opinion may blame foreigners, drug users, homosexuals, sex workers, or other disenfranchised populations for a health threat. Intense conflicts between public health and human rights occasionally arise, with members of the public or politicians claiming that it is necessary to ‘get tough’ on persons who transmit disease. An overly coercive policy may discourage persons at risk from coming forward for testing, counselling, or treatment. Health care professionals then lose contact with persons likely to spread disease, ultimately causing greater harm to the public.\textsuperscript{90}

**Step six: If a coercive public health measure is truly the most effective, least restrictive alternative, base it on the significant-risk standard**

The significant-risk standard permits coercive measures only to avert likely harm to the health or safety of others. The determination of significant risk requires public health inquiry. Significant risk must be determined on a case-by-case basis by means of fact-specific, individual inquiries. Blanket rules or generalisations about a class of persons are inadequate.
For infectious disease such as HIV/AIDS or tuberculosis, the significant-risk standard is based upon four factors: (1) the nature of the risk (that is, the mechanism of transmission); the probability of the risk (that is, how likely is it that transmission will take place); (3) the severity of the harm (what would the harm be to someone if the infection were to be transmitted); and (4) the duration of the risk (the length of time that the person will be infectious).

Step seven: If a coercive measure is truly necessary to avert a significant risk, fair procedures must be guaranteed to persons affected.

International human rights standards require that governments provide a fair public hearing before they deprive individuals of liberty, freedom of movement, or other fundamental rights.

An independent court or tribunal must adjudicate the dispute. The person whose liberty is threatened is entitled to advance notice of the hearing, representation, and an opportunity to present evidence.

The aim is to ensure a more accurate fact-finding process and greater equity and fairness to individuals who face a loss of liberty. Hearings give public health officials the opportunity to review their general approach to the health problem, as well as the human rights impact in an individual case.

CONCLUSION

Public health programmes that respect human rights will encourage individuals and communities to trust and co-operate with public health authorities. Promotion of human rights, particularly among previous disenfranchised groups, increases their ability to protect their own health. Finally, the right to health is a basic human right, related to and dependent on many other human rights. A human rights impact assessment provides a tool “to achieve the best possible public health outcomes while protecting the human rights of individuals and populations”.91

Nearly three decades on, the HIV and AIDS epidemics have had major impacts on how we look at health from the perspectives of human rights, human development and security. The effectiveness and long-term sustainability of the global response to HIV and AIDS require that prevention, care and support be mainstreamed in all civil, political, economic, social and cultural actions. But this process should
not detract from this historical human challenge. For the successes and failures of our response to the HIV and AIDS epidemics will continue to suggest new ways to advance health and human rights.
Chapter three: A rape-supportive culture?

The question is often asked; does South Africa have a rape-supportive culture? Certainly the figures that are released, even taking into account under-reporting, would seem to suggest that it does. South Africa has also been given the dubious distinction of being the rape capital of the world. How does such a ‘supportive culture’ develop? This is a difficult question to answer, touching as it does on issues of gender, patriarchy, power and identity but Rachel Jewkes has suggested that the country’s past is to blame for the very high levels of interpersonal violence experienced. Many people have been extremely brutalised by the political violence in our past, the disruption of families and communities, high levels of poverty and the very high level of violence of all forms. Much of this violence is directed towards women and children – a result of the marked gender inequalities in our society, a culture of male sexual entitlement and a climate of relative impunity in which rape is perpetuated.93

There are in South African society many factors which may contribute to women’s vulnerability to rape.94 These include a lack of information about and understanding of rape; women’s subordinate relationship to men; socially reinforced physical weakness and passivity; isolation from other women; and isolation in the community. In a country with such high levels of rape, rape should be made a public issue and debated and discussed so that all women know and understand their sexual rights. The tradition of blaming the victim95 and the ‘normalisation’ of rape are achieved in the ways a society deals with the action.

A common belief about rape is that it takes place between people who do not know each other. This is very often not the case. Many women are raped by their partners or dates or other acquaintances. Similarly, when children are sexually abused it us usually not by strangers but by a male relative or family ‘friend’ – men who have power over the child which they can use to force or persuade a child to have sex with them.96

Sexual violence within as well as outside sexual relationships has far-reaching public health and human rights implications. Partly because it has been shown to affect individual vulnerability to HIV and AIDS sexual violence has
in recent years become framed as a global public health issue. Woods et al. and Niehaus both reflect that the definition of rape above forced sex lies in the nature of the relationship between the two parties and the sexual culture in which sexual acts take place – with interlinked ideas relating to exchange, sexual entitlement, love and the notion of intention or violation or deserving. While the discussion often focuses on the behaviour and intention of the men, it is also the expectation of the women in the relationships that needs to be addressed.

POST-EXPOSURE PROPHYLAXIS

The issue of rape and sexual abuse is one where both public health and human rights are crucial, but in South Africa neither have been sufficiently recognised in the ways in which people who have been raped are treated. Beyond physical violence, rape and sexual abuse pose many issues for the people involved. For women there is the risk of pregnancy. For both men and women there are the risks of possible HIV infection and infection from other sexually transmitted diseases. For the person accused of rape there is the issue of being compelled to have an HIV test.

Levels of rape and other forms of sexual assault in South Africa have been the subject of international attention and condemnation over the past ten years. It has also been suggested that in South Africa, rape has one of the lowest conviction rates of all serious crimes. The Department of
Justice and Constitutional Development figures show that of more than 54,000 cases of rape reported in 1998, fewer than 7% were prosecuted. In contrast, however, South Africa is known for its commitment to constitutional rights and protections and for engaging in progressive legal reform processes.\textsuperscript{100}

The process

A woman has just been raped. She’s terrified to report to the police and lay charges, but she’s equally afraid that she could develop HIV. Thanks to friends she’s managed to get to a hospital where she can ask for post-exposure prophylaxis (PEP) – a 28-day course of antiretroviral drugs that will dramatically reduce the likelihood of infection.

At last she’s across the desk from a doctor whom she hopes will help her get the medicine she needs. But the first thing the doctor does is hand over a form. This is what it the form says, right at the top, even before it asks for her name:

\textit{... If you have not been the victim of a sexual offence, or act on behalf of someone who has not been the victim of a sexual offence, and abuse this procedure to establish another person’s HIV status with malicious intent, you may be prosecuted and convicted of an offence and sentenced to a fine or to imprisonment for a period not exceeding three years. You may also face a civil claim for damages.}

This is life after the new Criminal Law (Sexual Offences and Related Matters) Amendment Act of 2007: you’ve just had a glimpse of its often bizarre and counter-productive expression of commitment to the rights and needs of rape survivors.

A central thesis of this Review is that when the legislature makes decisions about dealing with the HIV epidemic that do not properly factor human rights into the equation, then the decisions can becoming self-defeating and even worsen the situation. The new law on sexual offences seems set to become an excellent example of this unfortunate type.

The Act broadens the definition of rape to include all forms of penetration without consent irrespective of the gender of either person or manner of penetration. This new definition is especially important for sexual crimes against children and will ensure that all invasive sexual offences carry the appropriate penalties instead of some being treated as less serious.\textsuperscript{101}
More than 50,000 rape cases were reported in South Africa in 2006 – almost 150 per day. Based on reported cases alone South Africa has 114 rapes per 100,000 people compared to 32 per 100,000 in the United States, according to police figures. However, women’s rights groups estimate that only one in nine rapes is reported to the police.102

Chapter five of the Act deals with “services for victims of sexual offences and compulsory HIV testing of alleged sex offenders”, and it is this section that concerns us most. This heading is somewhat misleading given that only one service, post-exposure prophylaxis or PEP, is provided for – which was in any case already available to rape survivors following a Cabinet decision taken in April 2002. Depending on how terms such as ‘reports in the prescribed manner’ and ‘designated health establishment’ are interpreted, rape survivors’ access to PEP could be narrowed down even further.103

This provision is in stark contrast to what was originally envisaged by the South African Law Commission (SALC) discussion document on sexual offences. Section 22 of the SALC’s draft legislation, headed ‘The provision of treatment’, stated

• If a person has sustained physical or psychological injuries as the result of a sexual offence,

such person shall, as soon as is practicable after the offence, receive the best possible medical care, treatment and counselling as may be required for such injuries.

• The state shall bear these costs.

The type of comprehensive response recommended by the SALRC is essential in the light of the serious health consequences of sexual violence and coercion.104 The AIDS Law Project (ALP), along with many other groups, expressed concern and submitted comments about the draft Bill. In its critique, the ALP stressed that its arguments and recommendations were all based on “human rights considerations with an emphasis on women’s health and equality”.105

How to test

In its comprehensive comments, the ALP urged that a specific provision should be included in the new legislation in terms of which the state would offer rape survivors the quickest, most accurate and effective method of testing for HIV. This is the Polymerase Chain Reaction (PCR) method of HIV testing. It should be provided to all survivors of sexual assault, including but not limited to rape. Other tests to establish whether someone has HIV have a window period of between three weeks and six months, while
PCR tests offer a diagnosis within 11 days. While PCR testing used to be prohibitively expensive it is now affordable, and “can provide peace of mind and certainty to survivors who fear that they may have been exposed to HIV by rape or sexual assault”.\(^{106}\)

This form of testing has already been accepted for use in a number of state health care facilities. The ALP urged that if the sections of the draft providing for compulsory testing of alleged offenders were approved, then PCR tests should be used for alleged offenders who are in terms of the legislation subject to compulsory HIV testing under certain conditions, as well as for survivors of sexual assault.

Most state facilities currently test for HIV using ELISA, Western Blot or rapid HIV tests. These tests test for the presence of HIV antibodies. The PCR test, however, confirms the presence of the virus RNA or DNA directly. Due to the long window period associated with antibody tests, rape survivors are subjected to the trauma of not knowing whether they have contracted HIV from the rape for several months. “However, if PCR tests were made available to all survivors of rape and sexual assault, survivors could obtain this peace of mind by being able to ascertain, within 11 days of the assault, whether or not they have contracted HIV”.\(^{107}\)

The ALP’s recommendation was to change the definition of HIV test in the legislation to the following: “any validated, medically recognised and most virally sensitive test for determining the presence or absence of HIV infection in a person”.\(^{108}\) If compulsory testing of offenders was to be introduced, it should be via PCR testing, not antibody HIV tests, the ALP said. This would give more reliable information to everyone involved.

**How to offer support**

Given that the state’s intention was to reduce the level of trauma experienced by anyone who had been raped, and indeed to recognise that people who had been raped had special needs, a comprehensive, state-provided, package of care needed to be provided to all survivors of sexual assault – and that care should not be limited to the provision of PEP at “certain designated facilities”.

However, the legislation passed did not go further than providing emergency antiretroviral access. The Act provides for post-exposure prophylaxis (PEP) against HIV infection which does not require that the case is first reported to the SAPS. This supports Department of Health guidelines which currently provide for PEP to be given to sexual offence victims without a charge having been laid with the police.\(^{109}\)
Despite the recommendations of the SALRC, the Act makes no provision for ‘psycho-social support for rape survivors’, and does not commit the state to providing resources for such services.

This is of great concern, as medical, psychological and social support for rape survivors is of vital importance in dealing with the trauma of rape and its aftermath. Without in-depth counselling to enable the survivor to understand the complexities of HIV transmission, including window periods and the risk associated with different types of exposure, it will be difficult for most survivors to make an informed choice about whether or not to apply for compulsory testing of the alleged offender, and to understand the implications of the test result, whether the alleged offender tests positive or negative for HIV. For example, if an alleged perpetrator tests HIV negative, a survivor who has not had access to proper counselling may make a decision to prematurely terminate PEP, without understanding that the perpetrator may be in a window period, with the result that the survivor may contract HIV. Whether or not she is infected with HIV, the worry that she may have been will, for some women, add to the trauma of rape. They will feel frightened about getting AIDS. They may worry about infecting others yet, in some cases, feel too afraid to tell their partners in case they might leave them or become violent. They may even have to deal with the possibility that it was not the rapist who infected them but their own partner. These are difficult and complex issues to deal with in conjunction with the emotional after-effects of rape.

How to respond

Had the law ensured that government should provide access to comprehensive health services it would have then has to deal with another possible route of infection.

In addition, as Vetten shows, citing the WHO, women who experience sexual assault, whether as children or adults, are more likely to attempt suicide than women who have never experienced such assaults. Other mental health problems associated with sexual violence include depression, generalised anxiety, reduced self-esteem, panic phobias and post-traumatic stress disorder. Whether or not she is infected with HIV, the worry that she may have been will, for some women, add to the trauma of rape. They will feel frightened about getting AIDS. They may worry about infecting others yet, in some cases, feel too afraid to tell their partners in case they might leave them or become violent. They may even have to deal with the possibility that it was not the rapist who infected them but their own partner. These are difficult and complex issues to deal with in conjunction with the emotional after-effects of rape.
made the point that health care providers, the police and the courts should recognise fully that rape entails serious consequences beyond the physical act. In addition comprehensive support can play a role in preventing further victimisation. It is here that public health and human rights could have acted powerfully in concert to address the needs of people who have been raped or sexually abused, and those who have been accused of rape or assault. A package of services (including counselling, treatment, social support, education and care) would have set a powerful example of how the public health system can act to promote and support the rights of people who have been attacked and ensured that the dignity of people who have been raped or sexually abused (as well as the rights and dignity of those who are accused) are protected.

It may be, however, that rape and sexual assault touch on the difficulties associated with sex and sexual behaviour. In South Africa it is still the case that a significant number of people believe that the way women dress and behave raises their risks of being raped or attacked, and that there are cultural practices that determine how women should behave. It is very important that rape survivors are also offered emergency contraception to prevent pregnancy after rape and a broad-range antibiotic that will prevent the risk of contracting other infections from the rape.

Women who have been assaulted, abused or raped continue to live in a society that tolerates very high levels of violence. In a Gauteng study some years ago, eight in ten men believed women were responsible for causing sexual violence and three in ten thought women who were raped ‘asked for it’. Two in ten thought women enjoyed being raped. Among male youth who knew a woman who had been raped, 7% thought she ‘asked for it’. Nearly half the males surveyed said they had sexually violent male friends and nearly 50% of male youth said they believed a girl who said ‘no’ to sex meant ‘yes’. The new legislation provides that a rape survivor should have access to PEP, and should be given “medical advice and assistance regarding the possibility of other sexually transmitted infections” (section 31(3)(ii)). However, a person in such a position has other urgent needs as well. It is very important that rape survivors are also offered emergency contraception to prevent pregnancy after rape and a broad-range antibiotic that will prevent the risk of contracting other infections from the rape. Given the high levels of sexual violence and prejudice, ongoing psycho-social support and counselling is needed.
Does this set us back?

Despite some of the improvements offered by the Act there is still concern that that legislative measures which are not properly based on human rights can end up being counter-productive. In the years before the legislation was passed, access to PEP was simple and informal: no uniform provisions existed for its provision. People who needed to access this prophylactic treatment as a result of sexual assault could go to any health facility and ask for it. Every such facility should – at least in theory – have had stocks of PEP drugs on hand for treatment of its own staff in the event that they were needed, for example if there should be a needle-stick injury. No official paperwork was needed. No involvement of the health facility was required in the alleged rape or sexual assault. Nor were the police involved. It was regarded by all as an emergency health matter and treated as such.

Now, however, legislation has radically altered the situation. Only ‘certain’ public health facilities will be providers of PEP. Those providers will be ‘designated’ and the names of these establishments will be gazetted.

Given the high levels of rape in South Africa, PEP services should be provided at all health care facilities. Where a facility was not equipped to provide full coverage of PEP for all who requested it, they should stock at least ‘three-day starter packs’ with a referral protocol to the nearest facility offering full PEP services.

The legislation also makes provision of PEP to a rape survivor subject to “certain conditions”. These include laying a charge with the police, alternatively reporting the “alleged sexual offence” to a “designated health establishment”. The specific section dealing with where and how PEP can be accessed reads,

"Only a victim who (a) lays a charge with the South African Police Service in respect of an alleged sexual offence; or (b) reports an incident in respect of an alleged sexual offence in the prescribed manner at a designated health establishment contemplated in (the relevant) subsection .... within 72 hours after the alleged sexual offence took place, may receive the services contemplated ..."

Why is this necessary, one has to ask, when the survivor is not making claims against any specific person or laying criminal charges but simply seeks access to drugs that could well prevent HIV infection, and when the stated intention of the legislation is to minimise the trauma
experienced by the victim? If the aim is to create an atmosphere in which the survivor feels supported and cared for, the approach of the legislation in the way that it structures the alternative route to access PEP via health facilities, is inexplicable.

A national working group, which included 23 organisations, focused in particular on the challenges faced by adult and child survivors of sexual violence, especially on their difficulties in accessing post-trauma health services and whether the proposed regulations and mechanisms set up by the regulations would be helpful to survivors or not. Much of what this group of organisations says dovetails with other submissions made. In particular, the submission explains and underlines how the draft regulations will reduce, rather than facilitate and enhance, access to PEP and other health services.

Speaking of the proposed regulations, published in March 2008 for comment, the national working group says PEP must be started as soon as possible and no later than 72 hours after the rape. “Anyone presenting after this 72-hour period is no longer eligible for PEP and (is) thus at risk of HIV infection”.116 In addition, research has clearly illustrated that PEP “cannot be provided in isolation from the whole range of health services which survivors should access immediately after sexual violence”.117

This same study highlighted how

...adherence to PEP is made more likely in the context of a comprehensive health response to rape survivors – including attention to their mental health needs. Further, because adhering to PEP for the required 28 days, and in the prescribed manner, is challenging for rape survivors, it is essential that this service be provided by those knowledgeable about both the ARV drug regimen, as well as rape.118

The need for “holistic, integrated health care” for survivors of sexual assault has already been recognised by the Department of Health itself in both its National Management Guidelines for Sexual Assault Care and its National Sexual Assault Policy.

In addition, a multi-sectoral policy document, the HIV & AIDS and STI National Strategic Plan 2007-2011 (NSP), endorsed by all government departments, clearly commits government to focusing attention on gender-based violence.

Objective 2.9 of the NSP reads: “Increase accessibility and availability of comprehensive sexual assault care including PEP and psychosocial support” and the required intervention is to: “[i]ncrease the proportion of facilities offering the comprehensive package of sexual assault care.”

The national working group says PEP must be started as soon as possible and no later than 72 hours after the rape.
Similarly, Objective 19.2 reads, “[e]nsure implementation of existing laws and policies that protect women and children from gender-based violence” and the required intervention is to “[e]nsure that the National Sexual Assault Policy and Management Guidelines are implemented by health care workers in all districts.”

The Act is potentially in tension with these aims because it detaches the provision of PEP from other health services to rape survivors by locating these in separate, designated facilities. Rape survivors need then to visit three different sites in the aftermath of rape: the police, a medico-legal facility and a health facility providing ART. The draft regulations also place the onus upon rape complainants to obtain access to PEP. This may discourage rape survivors from obtaining PEP timely.

The regulations include forms which must be completed by the person reporting the incident and officials of the medical facility at which help is sought. The approach contained in these forms was illustrated earlier in this chapter, with reference to a section that threatens prosecution if a false claim is made leading to someone being tested to ascertain his HIV status. The threat of criminal sanctions made at this particularly vulnerable point in a rape survivor’s life appears inappropriate.

Survivor trauma

The national working group also says,

*The focus at the health facility is on providing emergency treatment to a survivor, and it is not appropriate for a survivor to be subjected to questioning ... at this stage since it would cause secondary trauma, deter survivors from accessing health services ... and place an undue administrative burden on health care workers and medical practitioners.*

The National Sexual Assault Policy sets out the relationship between health services and the police. The *Service Charter for Victims of Crime 2007-2011* further commits the police to ensuring that rape kits are properly managed and that victims are transported to doctors and hospitals and back home. Such policies are important because many rape survivors do not have access to transport and depend upon the police to assist them obtain health care post-rape. Long waits affect women’s right to emergency medical treatment in the form of PEP since PEP should be taken as soon as possible after rape and no later than 72 hours later. Problems with transport are particularly pronounced in rural areas, as well as historically disadvantaged urban areas.
Section 2(2) of the Regulations imposes a duty on police to inform the victim of her right to PEP. The Regulations however limit this duty to simply providing her with Form 2 as well as a list of designated health establishments.

It is important that the police are fully aware of these provisions and able to act accordingly. One of the reasons given for women not reporting rape is that they fear the treatment they will receive at the hands of the police. Police tend to view women as having provoked the assault or rape. Police use their discretionary powers to establish whether or not an incident is ‘criminal’ or warrants investigation in ways that replicate traditional interpretations – often based on stereotypical assumptions – of what constitutes ‘real rape’ and what is considered ‘criminal activity’. This is sometimes related to what police perceive to be acts that occur ‘naturally’ within intimate or social interactions and what they perceive as constituting a genuine incident of rape. Likewise it is essential that all stages of the criminal justice process – reporting, forensic medical examinations, statement taking, investigation/information gathering and arrest of the accused – are of high quality.

**WHAT OF THE ACCUSED?**

The AIDS Law Project also said that it was concerned about provisions that survivors could enforce HIV testing of alleged offenders, given the “absence of ... adequate counselling and support for survivors.” The provisions of penalties to be imposed if compulsory testing was misused “creates the potential for secondary victimisation of the rape survivor”. It suggested that in most cases, if victims were given the PCR test it would provide the same peace of mind as would be obtained by testing the alleged offender. It said that such an arrangement was to be preferred to compulsory testing of the alleged rapist.

There are very low conviction rates for rape in South Africa. There is a conviction in approximately one in ten reported cases of rape of a girl under 18 years, and less than one in twenty perpetrators of reported adult rape are convicted.

In these circumstances, Section 41 would allow a perpetrator who could not be convicted due to lack of evidence to lay a charge against a complainant who used the provisions of Section 33 (1) to ascertain his HIV status. This would further traumatise the survivor by drawing her into another lengthy court case, this time as the accused, forcing her to
incur costs for legal representation, and preventing her from putting the original ordeal of rape behind her.\textsuperscript{124}

One of a number of related concerns raised by the National Working Group is what would happen if a survivor, after making such an application for the status of the alleged offender to be tested, withdrew the criminal charge. “Could [such a victim] be liable for prosecution? How does one guard against this risk?”\textsuperscript{125}

WHAT ABOUT CHILDREN?

The ‘sexual grooming of children’ is another new crime established by the Act and refers to the process through which offenders sexualise children over time. Grooming children for sex takes place gradually, often beginning with innocuous enough affectionate behaviour between adult and child and progressing to increasingly more intimate touching and fondling. It often also includes showing children pornography.\textsuperscript{126}

The AIDS Law Project, along with others, raised concerns about the way the draft legislation dealt with pornography as, in its view, the restrictive definition contained in the proposal could affect material used to teach teenagers about safer sex. Their submission quoted findings by the Reproductive Health Research Unit of Wits University which had conducted one of the largest national surveys among children and youth in South Africa.

From the survey it was clear that children were having sex at a young age and that there were a high number of unintended pregnancies.

\textit{[These] research findings point towards the fact that HIV prevention messages are either not working, or are not working well enough and that children are engaging in unprotected and therefore risky sexual behaviour, which increases their risk of contracting HIV. It is vital that all children receive ‘life skills training’ which should include sex education, and in particular how to prevent HIV and pregnancy. Parents and teachers should be encouraged to discuss sex openly with children, and to draw on a variety of educational materials and illustrations.}\textsuperscript{127}

The problem appears that the definition of offences in the Act could make teachers vulnerable to prosecution if they carried out such education properly. In the view of the ALP, Section 22 in Chapter 3, read together with the definition of pornography provided under Chapter 1, could give rise to
a situation where an educator or parent might be charged with an offence for providing safer sex education to children.

Effective safer sex educational materials will inevitably need to show images or descriptions of people ‘engaged in a sexual act’ or materials that will fall into the category ‘sexual conduct’ such as ‘masturbation’, ‘male genital organs in a state of arousal or stimulation’, stimulation of the female breast and ‘display of genital organs’ as provided in the definition of ‘pornography’ and ‘sexual conduct’.

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While it could be argued that this section allows for the lawful exposure of children to such materials, these provisions do not necessarily go far enough to provide peace of mind to parents and educators. The law needs to provide clarity and certainty, especially if its breach results in criminal sanctions. We cannot expect health educators or counsellors to execute their jobs and be comfortable providing sex and life skills education with the vague defence that what they were doing was not unlawful.

The Bill defines a child as ‘a person below the age of 18 years’, and thus effectively prohibits the dissemination of highly explicit safer sex education to a group of people who are at a tremendously high risk of contracting HIV. This is clearly not the intention of the Bill, but it could have the effect of discouraging legitimate sex education in homes and schools.129

In conclusion, this chapter has examined the fact that coercive legislation, intended to help survivors of rape and sexual abuse, can have unintended consequences which make their position worse. Much of this could have been avoided if proper input on the human rights of those involved as targets of the legislation had been obtained.
Protest Violence Against Women

WOMEN UNITE!

TAKE BACK THE NIGHT
Two recent interventions in HIV and AIDS serve well to highlight the tensions between a human rights approach and a public health response. As pessimism grew that prevention programmes were not successful enough, and as the realisation took hold that the epidemic in Southern Africa showed little signs of abating, people searched for other ways to address the issues of behaviour change. Two interventions have been promoted by public health as solutions to the issues of behaviour change and prevention of infection. While both of these interventions masquerade as prevention, in fact neither are. Both serve to place prevention firmly back in the clinics – back in the hands of public health – and back in a world in which little serious attention is paid to the social sciences and the complexities of people’s lives and choices. These two interventions are male circumcision and HIV testing – opt out, routine or mandatory.

**MALE CIRCUMCISION**

There’s something about the argument over male circumcision to help prevent HIV/AIDS that is reminiscent of the dispute concerning juvenile corporal punishment. Wide-scale therapeutic circumcision for males in areas of high HIV prevalence is a hotly debated matter, with articulate, high-profile and sometimes emotional supporters on either side; equally so the question as to whether young men in trouble with the law should be given a ‘good hiding’ rather than being sent to jail.

There are similarities in the ways that the issues have been viewed and argued. Both disputes, one current and one resolved by the Constitutional Court in 1995, deal with invasion of the bodily integrity of males. In both cases the invasion was defended with appeals to pragmatic considerations, including what is ‘best’ for the individual concerned and for society. In both cases, opponents of the interventions have appealed to human rights discourse in order to fend off the interventions.

When the case of juvenile whipping came to the Constitutional Court, it was to test the validity under the Bill of Rights of this form of punishment for young male offenders. At that time it was a sentence often imposed as an alternative to imprisonment. A full bench of the Cape Provisional Division considered five matters involving several young men convicted and sentenced by different magistrates.
All had been sentenced to “moderate correction”, meaning they were to receive a number of strokes with a “light cane”. The three judges decided that a ruling was needed on whether this form of punishment was constitutional. They consolidated the cases into a single matter and referred it to the Constitutional Court.

The argument made by those defending the legislation was, crudely put, that the law offered a form of protection to those who underwent the process, and thereby also protected society. The imposition of limited pain on youths in the form of corporal punishment would save them from a far worse fate (namely, imprisonment along with adult offenders) and offer them hope for the future (in that it protected them from becoming worse criminals). Bodily invasion could thus protect them from becoming adult criminals.

Members of the lobby opposed to this form of punishment also said they wanted what was best for the youths involved. However, they did not believe youngsters should be subject to a painful and degrading experience, since section 10 of the Constitution guaranteed respect and protection for a person’s dignity. Corporal punishment was not compatible with respect for the dignity of the person being punished. Section 11(2) of the Constitution prohibited the use of cruel, inhuman and degrading treatment, but the whipping of young men was exactly this. Finally, juvenile whipping infringed the rights of a child to security and protection from abuse.

The Constitutional Court ultimately found that punishment could not be justified under the Constitution, that the relevant section of the Act was unconstitutional and that no further sentences under this section could be carried out. The court made a number of comments (to be discussed later in connection with the circumcision issue), which also sound strangely relevant to both debates.

Proponents of circumcision have suggested that mass circumcision could greatly help reduce infection rates. Male circumcision has been practised in a variety of cultures going back thousands of years. The extent of the ‘cutting’ involved has varied, as have the overt, publicly announced reasons for the procedure. A number of years ago researchers began to question whether male circumcision could influence transmission of HIV/AIDS, and since then several studies have been undertaken. The most famous has been at Orange Farm in South Africa but there have been other major studies, in Kenya and in Uganda.

Proponents of circumcision have suggested that mass circumcision could greatly help reduce infection rates (female to male), as it is claimed that circumcised individuals gain “a substantial protective benefit against HIV acquisition”. Extrapolating from the studies, claims are made that if male
circumcision were practised universally in sub-Saharan Africa, 5.7 million new cases of HIV infections and three million deaths could be prevented over 20 years.

During the 16th International Conference on AIDS in Toronto held during August 2006, male circumcision was often hailed by speakers and delegates as the newest tool for prevention,\textsuperscript{132} and the process of making male circumcision widely available is now a matter being tackled by many agencies, particularly because of the qualified support for such programmes by WHO and UNAIDS.

Announcing the findings of the three trials, commentators in \textit{The Lancet} stated that acceptance of the clinical evidence that male circumcision is effective in preventing transmission of HIV does not automatically imply that governments and international organisations should initiate circumcision programmes. Before male circumcision can become health policy, countries need to develop capacity to educate and counsel people about the operation. “The challenge will be on how to convey the public health message that although circumcision reduces the risk of HIV, it is nevertheless necessary to always use a condom because circumcised individuals can still become infected” (our emphasis).\textsuperscript{133}

Here is the perplexing part: a public health intervention that relies on educational and human rights messages about safer sex, respect and condoms, but people delivering these messages have not been consulted widely about the implications of the potentially conflicting messages.

Most backing for rolling out circumcision interventions came from medical scientists. On the other hand, sociologists, anthropologists, community educators, and some community and political leaders questioned the idea. There was also serious concern about the missing dimension of human rights.

As Dowsett puts it, the international HIV/AIDS field was dominated by discourses “that favour medical intervention and morally sanctioned control over community mobilisation and activism for establishing and sustaining changes in behaviour”.\textsuperscript{134}

Three questions were raised by those who urged a more cautious approach:

- Why, they asked, does a country such as Lesotho, which already has a very high number of circumcised men, have one of the highest HIV incidences in the world?
- Why are programmes for male circumcision being planned before it has been established whether women
partners of men-to-be-circumcised will benefit by way of reduced transmission and infection, particularly since it is known that women are bearing the brunt of the epidemic in terms of numbers and ease of transmission?

- If a man undergoes therapeutic circumcision in order to reduce his risk of acquiring HIV, how will the protected status he perceives himself to have achieved through surgery impact on education efforts to ensure behaviour modification, safe sex, using a condom, etc.?

“What at Toronto, sociologists and anthropologists in particular were sceptical of the narrow form of ‘science’ being touted as the only form of evidence needed,” says Gary Dowsett. “Activists and practitioners, for example, people living with HIV and AIDS, those working in the non-governmental sector and prevention workers – those who comprise the bulk of the ‘AIDS community’ – were concerned with a potential undercutting of their hard-won shifts in sexual cultures, in many places, towards safe sex practices ... Indeed, the clamour for circumcision silenced many questions, overrode any misgivings and swept sceptics to the sidelines.”

Further problems about male circumcision are that predictive modelling suggests an efficacy of 50-60%. As Dowsett points out, this is weak when compared with male condoms whose efficacy rate is 80-90%. The trials were also conducted in terms of best clinical practices, with the best safe-guards, infrastructure and personnel. Therefore we cannot tell from the results “what might happen or could be achieved” in a real world, non-clinical situation.136

What’s more, the push to implement mass circumcision in Africa, following three randomised clinical trials, is based on an incomplete evaluation of real-world preventive efforts over the long term... No field-test has been performed to evaluate the effectiveness, complications, personnel requirements, costs and practicality of proposed approaches in real-life conditions. These are the classic distinctions between efficacy and effectiveness trials, and between internal validity and external validity... [This push] misleads the public by promoting false hope from uncertain conclusions and might ultimately aggravate the problem by altering people’s behavioural patterns and exposing them and their partners to new or expanded risks.137

In a recent study, existing data, sourced from trials and field studies on the efficacy of male circumcision, was used in a mathematical model in order to try and “address some of the most pressing questions surrounding male circumcision”. Findings showed that circumcision “will not be the
silver bullet to prevent HIV transmission”, and “even the most effective intervention is unlikely to completely stem the spread of the virus.”

Another academic with grave misgivings about the circumcision project is Tim Quinlan, the research director of the Health Economics and HIV/AIDS Research Division, University of KwaZulu-Natal, Durban. “[T]his idea [of male circumcision] is neither as sensible nor as simple as it might seem,” he claims. Quinlan echoed an anxiety expressed by many AIDS education workers: they are concerned that men, circumcised in order to help with HIV prevention, will opt out of the hard-won behaviour changes that have taken years to instil. Among these practices is condom usage. Even the most bullish medical science advocate of male circumcision says that the circumcision intervention will not be sufficient on its own and that it should be accompanied by safe sex practices such as condom use. So the question that needs to be asked is this: given the difficulty in persuading men to use condoms for HIV protection, and given the personal inconvenience and pain involved in circumcision which is accepted because of the alleged transmission-inhibiting powers of the intervention, how many will be prepared to use a condom over a circumcised penis?

Quinlan suggests that in the light of the scientific inadequacies of the studies, the reason male circumcision is being touted in Africa as the best new method of helping control the epidemic can only be that experts are desperate: “Nothing else is working, so let’s try this.” What, exactly, are these “scientific inadequacies” Quinlan alludes to? The methodology and results of the three RCT studies show many inadequacies:

• All three studies were halted early, making it possible that treatment effects were overstated.
• Out of a total of 10 908 males, 64 circumcised and 141 uncircumcised men had contracted HIV by the end of the studies. But 703 participants were lost to follow-up during the trials, their HIV status unknown. This leaves the attrition rate far higher than the number who contracted HIV, possibly skewing the study findings to a great extent.
• In the Orange Farm trial, 23 of the 69 infections occurred in men who reported 100% condom use or no sexual intercourse during the observation period. In the Ugandan trial, the same occurred for 16 out of 67 new infections. This raises the possibility of non-sexual transmission through contaminated medical instruments, blood exposures, etc.
• Prior to these three studies, observational studies relating to circumcision and HIV-status showed conflicting
results. For instance, data from Malawi in 2004 show an incidence of 9.5% in uncircumcised men, and 13% in those who were circumcised. This should at least call into question the three RCT’s unanimous results.

- Lastly, certain conditions were present in the three RCT studies that are very unlikely to be replicated in real-world settings. Some of these include repeated reinforcement of condom-use and safe-sex practices; the provision of two years of medical care; remuneration for participation; the solicitation of participants who wanted to be circumcised (thus not representative of the general population); and atypical sanitary and well-resourced settings that are not likely to be replicated in mass circumcision campaigns.\textsuperscript{139}

Quite apart from methodological considerations, many other issues should call into question the viability of mass male-circumcision as a public health intervention to stem the spread of HIV. What, for instance, will the effects of mass male circumcision be on marginalised groups such as women?

Sawires concedes that little is known about the impact a strategy of mass male-circumcision will have on women: “the degree to which male circumcision will benefit women as a prevention intervention, or potentially increase their risk of infection as a result of behavioural disinhibition, is uncertain and is a growing concern among public-health officials, social scientists, and policy-makers”.\textsuperscript{140} There is also very little known about the role of male circumcision in preventing transmission among men who have sex with men (MSM).

A recent study among black and Hispanic MSM in Los Angeles, New York and Philadelphia has indicated, however, that circumcised men were as likely to become HIV positive as men who were uncircumcised. Greg Millett of the CDC, who ran the study, reported that “Overall, we found no association between circumcision status and HIV infection status.”\textsuperscript{141}

Some studies question the effectiveness of circumcision as a method of controlling the spread of HIV because of its possible ill effects for women. A prevention study in Rakai province, Uganda, showed a trend towards a higher HIV incidence in the partners of HIV-positive men who were circumcised than in the partners of HIV-positive men who were not circumcised.\textsuperscript{142} This may very well be due to the false sense of security, about being protected or immune from HIV, circumcision creates. Risk-taking behaviour thus increases, which is likely to lead to a serious erosion of hard-won behavioural gains made by safe-sex campaigns in the past.\textsuperscript{143}
Wawer suggested that the explanation for the increase in HIV infections among partners of newly-circumcised HIV-positive men could be that couples resumed sex before the circumcision wound was “certified as having healed”. In addition, HIV-positive men might heal more slowly than men who are HIV negative. She said, “It is imperative people don’t resume sex in the post-operative period, and because of this slightly longer healing time we are saying don’t resume sex until six to eight weeks after the operation.”

According to Wawer, even in HIV-negative men, the benefit from circumcision did not appear until more than six months after the operation. Even this, however, is speculation. Recent evidence from the USA seems to contradict received wisdom by suggesting that the Langerhans cells in the foreskin may very well have an immunological protective function against HIV by producing the protein langerin.144

What’s more, it is unethical medical practice to extrapolate the results of studies performed on consenting adult men to a public health intervention that also applies to newborns. Newborns are not sexually active and therefore not at risk of HIV infection. Under human rights law, to circumcise an infant is in many ways similar to forcing the practice on an unconsenting adult.145

There is suspicion, particularly in the third world, that the strategy of male circumcision amounts to a new form of colonialism, particularly by the United States, which has the highest rate of male circumcision in the developed world, and given the fact that associations of medical practitioners in the first world are virtually unanimous in discouraging male circumcision among newborns. Sawires suggests that third world countries should be drawn into planning any further research or roll out in order to allay these fears.

This view was echoed, albeit rather strangely, by Robert Bailey who stated at the 4th IAS Conference on HIV Pathogenesis, Treatment and Prevention in Sydney 2007 that “the challenge ahead for us is how to roll out circumcision safely ... and to persuade leaders in countries that it is going to help their populations”. He went on, “circumcision is not simply a medical procedure, it’s tied to a complex web of cultural and religious practices and beliefs, so it’s not easy for politicians and ministries of health to very quickly come out in favour of circumcision in countries where it’s not traditionally practised.” He said that leaders in developing countries need to endorse circumcision “because international health authorities will not impose it – but the time to act is now – delaying the roll out of circumcision could be causing more harm, not just because more people are getting infected with HIV than necessary, but...
also because people are going to unqualified practitioners.” 146

The view sums up the arrogance of the public-health position well: “We will not impose this, but you need to do this despite very complex social, cultural and religious issues, which we have not taken the time to research”!

Sawes says further, “The uneven power relations implied by the way in which developed countries are doing trials in developing countries for a practice that has been declared medically unnecessary for babies in the West could give rise to a perception of new forms of colonialism. We now have the opportunity to change the discussion framework by ensuring that countries that stand to benefit the most or will shoulder the burden of potential harm have central leadership in the development of research agendas, as well as the assessment, planning and implementation of any intervention”. 147 In this connection it is interesting that both the Brazilian and Ugandan governments have decided against pursuing a strategy of male circumcision. 148

A statement on the subject, illustrating the perspective of young black people and thus the group most likely to be affected, has been produced by the African Youth and Adolescents’ Network on Population and Development, AfriYAN, which claims to have affiliates in 38 African countries. The organisation has been involved in the male circumcision debate for some time, in order to “come up with an African youth perspective on male circumcision”. As such, its views are instructive.

“We acknowledge that HIV and AIDS is one of Africa’s greatest challenges,” the statement begins. “National HIV prevalence among 15-49 year olds [goes] up to 40% in some countries and more than 50% of people living with HIV are youth ... Male circumcision alone as an intervention cannot be used as a strategy to fight HIV and AIDS. Male circumcision can only work as part of the already existing interventions to prevent ... transmission ... Circumcision is not the magic bullet in the fight against HIV and AIDS”.

They add: “There is a great need for people promoting male circumcision to young people to do more research and package the intervention in a way that won’t endanger young people with a false sense of security, through mixed messaging inadvertently resulting in youth engaging in high-risk behaviours”.

One of the glaring omissions from the medical scientists’ reports so far has been an assessment of the meaning of male circumcision in the societies where it occurs or has
occurred in the past. This is important to understand as it can help contextualise and explain local reaction to proposals for introducing or medicalising the procedure, as well as the subsequent behaviour of men who have been circumcised and of the rest of their community towards them. Peter Aggleton concludes that “Far from being a simple technical act, even when performed in medical settings, it is a practice which carries with it a whole host of social meanings”.  

He describes how in several African and Oceanic societies circumcision is part of a rite of passage into adulthood, and in these worlds the rite is linked with the meaning of being a man. He notes that male circumcision is also a religious ritual, particularly among Jews and Muslims. From his survey he concludes that circumcision plays a crucial role as an indicator of hierarchy and social differences. He says it is almost always “a strongly political act, enacted upon others by those with power, in the broader interests of a public good but with profound individual and social consequences”.  

Aggelton’s contends that male circumcision as a prevention strategy against HIV infection needs to be tested “through scale-up”, rather than immediately beginning a mass drive. Like other writers, he is concerned about the possibility that male circumcision could open up new divisions. “At the very moment when two decades of programming and advocacy are making headway against HIV-related stigma and discrimination, we run the risk of creating new physical and social differences around which division can solidify – between the circumcised and those who are not; between those who advocate for male circumcision and those who do not; and between those who favour a broad-based and comprehensive response and those who still search for seemingly simpler solutions”.  

We run the risk of creating new physical and social differences around which division can solidify – between the circumcised and those who are not.

In what way then, could one say that the debate over male circumcision shares elements of the dispute over juvenile whipping?

Medical scientists, and those who share their conclusion that male circumcision should be rolled out as a universal procedure for males in sub-Saharan Africa, claim that invading the bodily integrity of millions of African men, youths or boy children is a pragmatic answer to a problem. It is ‘best’ for the individual concerned and for society, they say. As with those who defended juvenile whipping, they would claim that the procedure protects those who undergo the process, and thereby also protects society: if the individual is protected from infection, the epidemic is slowed down. However, even if the effectiveness of mass male circumcision were the same as reported...
as in the three RCTs, it is estimated that if all African males were to be circumcised over the next ten-year period, the incidence rate in sub-Saharan Africa would only be reduced by 8%, while AIDS-related deaths would only drop by 1%.¹⁵²

To continue the analogy, the imposition of some relatively small pain on men at this sexually active or pre-sexually active stage of their lives saves them from a far worse fate (namely the emotional and physical pain of HIV infection); it offers them hope for the future in the form of a ‘second chance’ to be sexually active without becoming infected. Bodily invasion, therefore, combined with a change in behaviour which, it was hoped, would follow the physical pain inflicted on them, would protect them from the looming danger of becoming a signed-up member of the infected cohorts.

The notion that juvenile whipping was good both for the offender and for society finds an echo in Aggleton’s analysis of male circumcision: almost always “a strongly political act, enacted upon others by those with power, in the broader interests of a public good but with profound individual and social consequences”¹⁵³. Apart from circumcision, what could be more strongly political, more obviously imposed on others by those with power than the practice of whipping juveniles, a procedure described by Justice Langa as “[involving] the intentional infliction of physical pain on the juvenile by a stranger at the instance of the State”.¹⁵³

Just as some parents asked for the imposition of juvenile whipping as a punishment (instead of imprisonment), so we find research claiming that men in the communities under study requested circumcision and some (who were not part of the group to be circumcised in terms of the programme) even sought out circumcision themselves via alternative sources. Similarly, juvenile whipping was said to be convenient, could be meted out easily and efficiently, and was “quickly over with”. These remarks and justifications often sound like the arguments over who best to carry out circumcision procedures, where they should be performed and whether the end (reduced susceptibility to HIV infection) justified the means (circumcision).

Another analogy can be made in terms of the gender issues involved: in both cases the procedure is limited to men or boys. Just as juvenile whipping, generally restricted to boys, included as part of its unspoken historical and socio-legal meaning, the understanding that boys need tougher treatment than girls, and that their bodies should be controlled and shaped to take more ‘punishing
treatment’, so circumcision has often been regarded as part of the initiation of boys and men into the value placed on moral and physical control of the body.\textsuperscript{154} Fox and Thomson\textsuperscript{155} develop this idea even further. They write of the “harm/benefit assessment which lies at the heart of the male circumcision debate”, and suggest that the reason legal and ethical authorities have so often adopted a permissive attitude to circumcision comes from “traditional constructions of male bodies as resistant to harm or even in need of being tested by painful ordeals, and of female bodies, by contrast, as highly vulnerable and thus in need of greater protection”.

That leads to the question of what is being done about child protection in the debate about circumcision. Who is keeping a watching brief on behalf of the children and young adults who could be affected if the programmes go ahead as planned? Who will ensure that their human rights are respected and intervene in time if they are not?

For part of the answer we should go back to the dispute over whether juvenile whipping should be declared unconstitutional even though many sectors of society – including some parents – believed it was in the best interests of young men, for we cannot avoid considering the role that lawyers and the courts should take in defence of human rights.

What is absolutely clear from a consideration of the Williams case is that the Constitutional Court encourages presiding officers, as part of their constitutional duty, to be concerned about the role they must play in promoting a new culture based on human rights.

Similarly, it is not only medical experts on HIV/AIDS who should be involved in the debate about male circumcision. It is a matter that involves the fundamental rights of those who might undergo this procedure, and all those making policy decisions have to consider these human rights issues, along with the myriad other questions that human rights advocates ask, before making any decisions about how to respond to calls for mass roll-out of male circumcision programmes.

As Justice Langa said in S V Williams, “[I]t is incumbent on structures set up to administer justice to ensure that as far as possible, these [fundamental] rights, particularly of the weakest and the most vulnerable, are defended and not ignored”.

Male circumcision leaves far too many important questions unanswered for it to be considered a viable public health intervention. Some of these include insufficient data for a real-world setting, the possibility that it might lead to increased infection rates due to increased risk-taking, it
constituting an unethical medical practice, and the availability of more effective prevention strategies.\textsuperscript{156} One may very well ask why, then, is male circumcision seen as a cure-all to the epidemic? A large part of the answer lies in the biomedicalisation of HIV, combined with the power of public health as a discourse in establishing ‘social facts’. Is all of this merely a new way of ordering and regulating the bodies of Africans – as those in power in the West see fit?

**VOLUNTARY VERSUS ROUTINE HIV TESTING**

Because of the large proportion of people in need of treatment who still do not know their HIV status in the developing world, there have been calls to find ways to get more people, particularly men, to be tested and, it is said, have the possibility of treatment. An approach in which requirements for pre- and post-test counselling and informed consent are relaxed is being advocated by some. The question is being asked: does the scaling up of treatment mean that it might be necessary to provide HIV tests on a more routine and streamlined basis, even if this means simplifying (and possibly reducing) pre-test counselling requirements, and weakening standards around confidentiality and disclosure of HIV test results?

The urgency of placing millions of people on ARV treatment in a short time has led some experts, such as Kevin de Cock of the US Centers for Disease Control and Prevention (CDC), to argue that traditional safeguards such as pre- and post-test counselling, confidentiality and voluntariness should not stand in the way of widespread HIV testing. Widespread testing, it is argued, will both facilitate increased access to HIV treatment and prevent new HIV infections by bringing more people into the health care system, enabling provision of information about how to prevent HIV transmission. In addition, widespread testing is thought by many to reduce HIV-related stigma and discrimination by ‘normalising’ the disease. As more people learn their HIV status, it is argued, HIV/AIDS will come to be perceived as yet another chronic, manageable illness such as cancer or heart disease.

In this respect, calls for mass HIV testing (sometimes referred to as ‘routine testing’), depart from the ‘AIDS exceptionalism’ school, which posits that HIV testing should be approached with exceptional caution due to the stigma and human rights abuses associated with the disease.

At the heart of this debate is the policy being considered, or indeed already being implemented in many parts of the developing world, that there be ‘routine testing’ in clinics, hospitals and other settings. ‘Routine testing’, which has for example been adopted in Botswana, typically means...
that anyone who comes into contact with the health system, for any health care problem, is automatically invited and strongly encouraged to take an HIV test. A corollary of this definition is that traditional safeguards such as voluntariness and full pre- and post-test counselling need to be compromised in the interest of public health. Testing would still be strictly voluntary under a routine testing scheme, but patients would not have access to the same level of information and counselling before choosing whether or not to test. Thus, in a sense, routine testing implies an incursion into individual rights (to voluntariness, information, and confidentiality) for the sake of the collective good. Any ‘routine testing’ policy that does not give patients a clear, easy way to decline the test risks infringing the right to informed choice regarding whether or not to submit to testing.

Throughout the HIV/AIDS epidemic, mandatory testing has been rejected almost universally by public health experts. The Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO), both expert multilateral bodies that set international public health standards, do not support mandatory testing for public health purposes. Until recently, routine testing has also been rejected. There is good reason to pay heed to the slippery slope that leads from ‘opt-out’ (ostensibly voluntary) testing to mandatory testing. Those who propose a simplification of accepted pre-test counselling practices do not hide their utilitarian premise that a greater end (such as prevention of mother-to-child HIV transmission) justifies the means (of infringing individual rights by providing for testing without fully informed consent). Granted, these proponents agree that present conditions are not ideal, and should be rectified in the long term. But they also accept that the present justifies emergency measures.

One concern with this approach is that if ‘emergency’ measures such as routine opt-out or opt-in testing fail to reach the desired number of people, the next logical step under utilitarian principles might be to call for compulsory testing, either of selected groups (such as ‘high-risk’ groups) or for the population more generally. One must keep in mind here that diagnostic testing for tuberculosis and sexually transmitted infections already often goes beyond uninformed opt-out testing. The UNAIDS/WHO 2004 Policy Statement on HIV Testing also notes that many countries have mandatory testing in place for immigration purposes and for military personnel.

International human rights law recognizes the individual right to withhold consent to medical treatment, including diagnostic tests. This right derives from the principle of individual autonomy, which has its roots in the inherent
dignity of every individual. Testing for HIV without informed consent represents an involuntary intrusion into bodily integrity, which is protected by the right to liberty and security of the person in article 9 of the International Covenant on Civil and Political Rights. The only exceptions to autonomy and bodily integrity are –

- necessity (when the person cannot consent, e.g. due to unconsciousness, if there is no guardian to provide consent and if knowledge of HIV status is a treatment necessity)
- age
- legitimate statutory enactments authorising non-consensual HIV testing.

As the necessity exception does not apply to the context of routine testing to facilitate treatment scale-up, and age is not contentious in this context, the focus here falls on legislative enactment.

Any testing without informed consent thus has to be authorised explicitly by statute (or other law of general application, here referred to as ‘statute’), and cannot stem from ad hoc measures or variable operational guidelines. For such a statute to meet human rights standards, there must be overriding societal benefits, or a clear public purpose being served by that statute. Under international law (as well as under some domestic constitutions), rights may only be limited by way of laws of general application that pursue a legitimate aim responding to a pressing social need, and that are proportionate to that aim. In addition, governments must use the least restrictive means possible to achieve those aims.

Proponents of routine testing have argued that some curtailment of the right to informed consent may be justified to ensure that new medical advances, particularly antiretroviral treatment, will reach people living with HIV on a large scale. In the words of de Cock et al. –

It is hoped that earlier identification through routine testing of HIV-positive patients will allow earlier enrolment.

If the benefits of antiretroviral treatment and prevention of opportunistic infection are to reach the people who need them, routine diagnostic HIV testing will have to become standard practice in medical care.

Routine HIV testing should initially be concentrated in general medical and tuberculosis patients, but in the long term, testing and provision of follow-up information should become a routine component of all health-care interventions.

According to the official information provided by the Masa programme in Botswana, it is hoped that “earlier identification through routine testing of HIV-positive patients will allow earlier enrolment”. The Botswana Minister of Health justifies routine testing with reference
to the right of access to care, or: “the right not to die before your time because a doctor did not perform relevant tests and diagnostics”.

The goal of greater access to ARV medicines is unimpeachable. But the assumption that earlier identification of HIV cases through routine testing will achieve that goal, or is necessary to achieve that goal, is debatable. Indeed, some have argued that routine testing threatens to reduce uptake of ARVs by engendering a distrust of the health care system and creating a culture of forced medical treatment. In this sense, routine testing may not even be rationally connected to the laudable goal of increasing access to ARV drugs, at least for those individuals who would shy away from medical care for fear of being tested against their will.

There is, moreover, no guarantee that the tested person will indeed receive ARVs, due to the unavailability of these medications in many settings. If ARVs are available, there is no guaranteed benefit to the tested person, due to the general requirement that only HIV-positive people with a CD4 count of less than 200 qualify for ARV treatment. Thus, it cannot be assumed that the trade-off being proposed – universal treatment in exchange for a reduction in individual rights – even exists.

Knowledge of serostatus is not necessarily always a benefit to the person concerned. There is the danger of widespread public scepticism about being encouraged to test but then having no access to treatment and nothing to help with the result other than the longstanding advice to ‘live positively’. This is a difficult enough instruction in places where treatment is not even promised, but where taking an HIV test is premised on the hope for, or even the apparent promise of treatment, lack of access becomes all the more problematic. It also means ongoing testing until the mandated low T-cell count is reached. Continuous counselling will place an additional load on health care systems and staff that are already overburdened.

Proponents of routine testing frequently allude to the fact that a very small percentage of those estimated to be living

In most – if not all – developing countries, testing sites are limited and treatment rollout programmes are site-based rather than universal. The urban/rural divide often proves especially difficult to bridge in order to place testing and treatment within the grasp of everyone. Before countenancing an encroachment of human rights (by allowing for routine testing), policymakers should be certain that the promise of widespread treatment access is a real one and not a dim prospect.
with HIV are actually aware of their status, and that this impedes treatment efforts. Yet if fear of stigma is one of the reasons why people do not voluntarily seek HIV testing – and why those living with HIV choose not to disclose their status – then a mass programme of HIV testing without fully informed consent hardly seems a fair (and much less effective) response. The idea that routine testing will significantly reduce stigma shows little appreciation for the deep-seated sources of stigma, which go far beyond just the issue of a positive or negative result. In fact it is possible that access to treatment in this way, if associated with a reduction of information, counselling and support, and the introduction of an element of coercion and judgement may operate to make stigma very much worse. In a recent monograph on AIDS treatment in a rural South African setting, Jonny Steinberg eloquently sums up the tension between routine and voluntary testing. He writes about the thoughts underlying a Medicines Sans Frontieres programme in Lusikisiki:

*MSF believed that this fish-bowl approach to testing was the best way to combat stigma. Their message to those who walked into their testing centres was this: ‘Yes, there is ill feeling out there, but it doesn't matter. Yes, your community will know your status, but you will be okay. Once you realise that the hostility will not hurt you, you will have walked through an invisible barrier. You will have shaken off an unspeakable burden and an intolerable pain. Come with us, there are many of us, we will protect you.’ As Hermann Reuter said to me, ‘A person goes to test. If he tests positive, the people in his community will know, and he will make some enemies. But the friends he makes will be more important than the enemies. The people testing positive develop meaningful relationships, the sort of relationships they have never had. Before, they were sitting around and doing nothing. Now, their lives become meaningful.’ Whether this is the most effective way to get people to test and onto treatment and whether it is sufficiently cognisant of the right to privacy are questions about which there will always be a reasonable amount of disagreement.169*

For testing to succeed as a prevention strategy, information and counselling are essential. Yet routine testing seems more designed to channel HIV-positive people into treatment programmes than to counsel people about prevention strategies. There is scant evidence that such an approach will have a more beneficial impact on HIV prevention than, for example, increased access to voluntary counselling and testing (VCT) programmes.

There is an increasing argument that prevention and testing and treatment cannot be separated. While this is
true, it is also the case that treatment carries with it the danger of the medicalisation of prevention and a return to prevention being firmly located within the bio-medical paradigm.\textsuperscript{170} To what extent testing and treatment support prevention remains anecdotal. Blower and Farmer argue,\textsuperscript{171} however, that ARVs should be viewed as a prevention tool and not simply as a therapeutic tool. There is, they argue, ample reason to believe that prevention and care may be mutually reinforcing and overlapping activities.

However, placing testing and counselling in the context of clinical services repositions prevention as part of a public health response rather than of a social response. Although there are very many nurses and health care workers who are good AIDS educators and counsellors, on the whole the training of medical people predispose them to be judgmental (a good patient vs. a bad patient, a health-seeking client vs. a risk client, a compliant client vs. a irresponsible client etc). Many people feel unable to challenge the dominance of the power that health care workers wield.

But further, locating prevention in clinical settings risks de-emphasising the only truly effective prevention tools we have – responses designed and implemented by affected communities which empower individuals to achieve and sustain disease prevention behaviours. In addition, when in many clinics around half the individuals tested will be told their result is negative, individuals’ beliefs in the efficacy of what in reality are risky behaviours will be reinforced – further fuelling the epidemic.

It has also been argued that testing empowers “patients with the most critical information regarding their health”. But many people (especially women) may legitimately feel that they have more to lose from getting an HIV test than they have to gain. Far from being a means of ‘empowerment,’ routine testing and possible disclosure may make the position of women much more precarious. Not only is confidentiality of test results often breached, but as women are more likely than men to come into contact with the health system (largely because of antenatal services), routine testing may reinforce stereotypes about women being the principal bearers of HIV infection. Women may thus suffer very greatly from routine testing – emotionally, physically and economically. Unless tests are offered in an environment of establishing first what ongoing support the woman will need, what kind of support it is possible the woman may have and, in the absence of family or community support, who she will be able to turn to – the basic fundamentals of good pre-test counselling – she should not be offered the test. In addition, for many women the option to ‘opt out’ of HIV testing in the face of pressure from a medical professional will not be realistic.

In sum, the bio-medical solution of increased testing risks allowing policy-makers to escape their responsibilities.
Governments and other policy-makers have a responsibility for providing the infrastructure for sustainable prevention and treatment programmes and for creating the climate in which people want to know their HIV status and trust health care providers to provide to them both that information and concomitant support.

Roll out of treatment should not depend on paternalism and coercion. As it is, most health care systems are heavily burdened, with underdeveloped infrastructure. The focus should now be on strengthening these, to ensure the best functional system of treatment to those who make an informed choice to be tested, and be treated if they conform to basic criteria. Treatment should enhance prevention by making people want to know their status, not detract from it by introducing coercive medical procedures that foster distrust of the health system. Access to treatment is essential, must be supported and fast tracked, but it is essential that we get it right. The sense of pushing treatments ‘no matter what’ has to be challenged. There has to be a equally strong push for all the other rights that people have: the right to prevention, to counselling and support, to privacy and non-disclosure, to adequate food and follow-up health care, the right not to return for the result, and finally and absolutely, the right not to be tested at all.
One law for one nation
All involved in health care, including health users, are challenged to be ‘attorneys for the poor’ and defenders of the human rights to health.

– Nozizwe Madlala-Routledge, former deputy minister of health, December 2006

Most people reading South Africa’s Constitution will begin with Chapter 1, the founding provisions, or perhaps with Chapter 2, the Bill of Rights. But in fact there’s a section that comes just before either of these. Called the “Preamble”, this page-long statement, which has the same force in law as any other part of our supreme law, tells us the purpose of the Constitution, and why it was adopted by our democratically-elected representatives.

It says that “We, the people” through our freely elected representatives, have adopted the Constitution as our supreme law in order to –

- “Heal the divisions of the past and establish a society based on democratic values, social justice and fundamental human rights;

- Lay the foundations for a democratic and open society in which government is based on the will of the people and every citizen is equally protected by law;

- Improve the quality of life of all citizens and free the potential of each person; and

- Build a united and democratic South Africa to take its rightful place as a sovereign state in the family of nations.”

In many ways this is a summary of the rest of the Constitution, or at least of its spirit. It also speaks strongly to the point of this and the other chapters.

Among the many serious “divisions of the past” that must be healed is the scandalous inequity in health services that existed under apartheid. In its place it is necessary to establish a health system that is based on democratic values and that respects the fundamental human rights of our own Constitution as well as the international conventions on human rights. This will be the best means to “improve the quality of health of all citizens”.

It is easy to understand that by improving the quality of
health of the people of South Africa in a way that is respectful of human rights, we will at the same time be improving everyone’s quality of life.

This chapter examines three particularly vulnerable groups, all of whom should be able to depend on their rights to health, among others, being acknowledged and protected. All three groups are rendered more socially fragile by the HIV and AIDS epidemics. In all three cases, we have let them down. As a result, their health, our health, the public health system and the human rights of all suffer.

These vulnerable groups are
- children, including those in child-headed households and AIDS orphans;
- prisoners, and
- refugees, asylum-seekers and undocumented migrants.

For all three categories of people, the issue of the gap between rights and action is one that needs to be addressed. All three groups are, in one way or another, citizens (for migrants and refugees are citizens of another country—but owed protection by South African and international law) and as citizens, their access to rights and the fulfilment by the state and legal system of these rights is fundamental.

CHILD-HEADED HOUSEHOLDS AND ORPHANS: WHEN DO THE ‘VULNERABLE’ BECOME THE ‘VALUABLE’?

The situation of orphaned children, particularly those whose parents have died from AIDS, is one of great vulnerability. Despite efforts by the state to help, many of the fundamental rights of these children remain unmet.

The rapid growth of the problem is startling. According to figures from UNAIDS/UNICEF 2002, in seven southern African countries “the number of orphaned children to have lost both parents is projected to increase between 1990 and 2010 by a staggering 1 100%, from 250 000 to 2.9 million” between 1990 and 2010. The most recent South African country report (endorsed by the government) states that there were 1.5 million orphans due to AIDS in 2006. Furthermore, children under the age of 18 comprise 40% of South Africa’s population. According to the Avert website, there were 11.6 million orphans in Africa in 2007.

One of the main issues to be fully and critically debated is where the locus of responsibility for orphans lies. Commenting on this, the UNGASS declaration on HIV/AIDS, June 2001 stated in the declaration of commitment that states should “by 2003 develop and by 2005, implement
national policies and strategies to build and strengthen governmental, family and community capacities to provide a supportive environment for orphans and girls and boys infected and affected by HIV/AIDS, including by providing appropriate counselling and psychosocial support, ensuring their enrolment in school and access to shelter, good nutrition and health and social services on an equal basis with other children; and protect orphans and other vulnerable children from all forms of abuse, violence, exploitation, discrimination, trafficking and loss of inheritance."\(^{174}\)

While the number of AIDS orphans or the numbers living in child-headed households in South Africa is uncertain, there is also no unanimity about who should be included in the definition ‘child-headed household’. Some researchers only consider children to be orphans where both of whose parents have already died, but Sloth-Nielsen says there is a growing tendency to include another group of children: those whose care-giver is terminally ill with HIV/AIDS. “This is because children become heads of the household when their parents become too sick to do what is necessary to maintain the household. These children are as much affected or vulnerable as those who have already lost their primary care-giver”.\(^{175}\)

Although since the start of the HIV/AIDS epidemic there has been talk about the so-called ‘AIDS orphans’, there has been little serious planning about how societies might develop policy and programme responses to deal with a major social crisis and a situation of which most societies have no prior experience. There have, of course, always been young people who have been orphaned but the scale and the magnitude of the AIDS epidemic makes previous community and government responses inadequate.

UNAIDS, WHO and UNICEF define AIDS orphans as children who lose their mother to AIDS before reaching the age of 15 years. Some of these children have also lost, or will later lose, their father to AIDS. No matter how they are ‘defined’ there are going to be millions of children who will face a future without their parents and for whom creative policy and support decisions need to be made. Children are being affected economically, socially and psychologically. Economic and social impacts include malnutrition, reduced access to education and health care, child labour, migration and homelessness.

Most policy decisions and recommendations suggest that orphans should be placed with relatives or in extended families and that siblings should be kept together. No one would dispute the fact that where possible orphans should be in close families and placed with their siblings. And where this is happening, there should be real support for the family structure. What is essential is that policies
be developed for children for whom there is no extended family, where there is abuse or neglect of children or where the extended family cannot cope – who cares for young people under these conditions?

One way of addressing the issue of orphans, whether this be from AIDS or other causes, is to keep the mothers alive. There are, according to Kelly,176 two issues here: keeping mothers alive and healthy and keeping their children alive and healthy. Not only does the mother have a personal fundamental right to live, but she is also essential to preventing the disintegration of families. This raises the question of the right to access to treatment and good health care for mothers as well as for children.177

The combination of increasing orphan numbers, reduced numbers of care-givers and weakened extended families, combined with poverty, means that vulnerable children are far more likely to fall through the extended family safety net where this exists.178

The reality of families and communities

There are various ways in the South African context to define ‘families’ as well as to define ‘households’. This debate about what constitutes a family or household needs to be brought into wider debate as it affects access to welfare grants and social support. Approximately 6% of South African households are destitute and 40% of all households are vulnerable to slipping into destitution. On average 59% of any available family income goes towards paying for four items: food (18%), housing (16%), income tax (15%) and transport (10%). On average only 4% is spent on health care and 2% of household expenditure goes towards savings and investments.

Three in five children live in poor households and many children are exposed to public and domestic violence, malnutrition, and inconsistent parenting and education. Some 55% of people from poor households are unemployed and lack of access to basic services such as electricity, sanitation and piped water is also closely related to poverty.179

Families who are destitute or who have become destitute due to AIDS through illness or through taking in additional household members are, in addition, unable to cope with the psychosocial effects of HIV and AIDS. As well as the problems related to inadequate nutrition and lack of education and health care, there is the emotional scarring and depression which follows traumatic experiences and death. This in turn affects the socialisation and integration of children into traditional and social roles, norms and values,
and raises the risks of crime, instability, alcohol and drug use and social, economic and political displacement. In families that are living in poverty and just surviving, the taking in of additional young people means in effect that the life chances of all the children are affected. Whereas there might have been, for example, four young people taken into a family of six (two adults and four children) to protect those four children – the reality is that there are now eight children for whom there is not enough space, food, clothing, affection, time with adults, education or health care. In the debates about the care of orphans, little has been said about the impact on other children as well.

The rights of young people

In 1995, South Africa ratified the UN Convention on the Rights of the Child. This Convention is perhaps the most important international treaty dealing with all aspects of children’s rights, and it is a useful framework for addressing the rights of children in child-headed households.

One of the most important foundations of the Convention is the idea that children are best raised in a family environment. The Convention promotes the family’s role in realising the rights of the child. The Convention makes provision for alternative care where children do not have a family environment, or where they are removed from their families.180

According to Sloth-Nielsen, the Convention does not directly address the issues facing AIDS orphans and child-headed households. However, it has found an alternative mechanism to do this, namely through General Comments made and issued in terms of the Convention. General Comment No 3 (2003) deals specifically with what is called, “HIV/AIDS and the Rights of the Child”.

“The General Comment starts by saying that the issue of HIV/AIDS and children is often seen as being mainly related to health (our emphasis). It then points out that the impact of HIV/AIDS on children’s lives is in fact much wider, as it involves threats to their civil and political, social, cultural and economic rights (our emphasis). For this reason, the Committee recommends that measures to address HIV/AIDS must be holistic and rights-based”.

The General Comment points out to States Parties that discrimination makes children more vulnerable to HIV and AIDS. For example, children living in remote or rural areas, where health and other services are less accessible, are more vulnerable to infection. There is also extensive discrimination against infected children, which can lead to them being abandoned by families and communities.
As an overall strategy, the General Comment stresses that prevention, care, treatment and support reinforce each other. They provide a continuum within an effective response to HIV and AIDS. Education and children’s access to information about sexuality and HIV and AIDS are seen as crucial. Countries are encouraged to provide child-friendly health services and to make sure there is access to voluntary counseling and HIV testing. They must also offer knowledge of HIV status to children and adolescents, and provide confidential sexual and reproductive health services (including free or low-cost contraception). Finally, they must provide care and treatment, if needed, for HIV-related health problems, such as tuberculosis and opportunistic infections.183

As it is necessary to protect children’s rights, mandatory (compulsory) HIV testing is prohibited in international law. As the child’s capacities evolve, based on factors such as age and maturity, this will determine whether consent to HIV testing should be obtained directly from the child, or from a parent or guardian.

However, in all cases the confidentiality of the results must be protected. Information on the HIV status of children may not be disclosed in health and social welfare settings, or even to parents without the child’s consent.

Children. The focus should be on access to education, access to shelter, access to state benefits such as social grants, and access to health care services, as well as fair inheritance rights. Acquiring proof of identity has very important implications for a child, because it relates to securing his or her recognition as a person before the law ... Proof of identity also helps to protect other rights, including inheritance rights and the right to education.184

The General Comment acknowledges formally that child-headed households now exist. States Parties are encouraged to provide financial and other support to them. As a matter of policy, though, the General Comment says that communities are the frontline of the response to HIV and AIDS and other related consequences, such as child-headed households. States’ strategies must be designed to support them in deciding how they can best provide support to the orphans living in their communities.185

The best interests of the child?

Article three of the ICRC states that the best interests of the child shall be a primary consideration in all actions concerning children – whether undertaken by public or private social welfare institutions, courts of law, administrative
authorities or legislative bodies. Such an approach prevails in all cases – from direct interventions by the state in its jurisdictions to the private context of family life where states may intervene directly, to ensure and protect children’s rights.

Best interests of the child means that legislative bodies must consider whether laws being adopted or amended will benefit children in the best possible way.186

Article 19 calls on the state to protect the child against any form of neglect or abuse, maltreatment or exploitation and finally, for the purposes of this discussion document, Article 20 allows for the fact when a child has been temporarily or permanently deprived of his or her family environment, or in whose best interests should not remain in that environment that the state will provide special protection and assistance. In this Article provision is made for the state to provide alternative care and allow for foster placement, adoption or placement in suitable institutions for the care of the children.

Kevin de Cock, while at the CDC, believed that Africa and international agencies need to put aside all preconceived ideas and develop some radical new thinking about how to care for orphans and reduce the number of future ones.187 He added that orphan prevention programmes are inseparable from those aimed at public health problems like malaria, malnutrition and diseases prevented by vaccines – but public health has not been brought to bear in a major way on orphanhood and other AIDS problems.188

Access to education, health care and social support are covered in other Articles of the IDRC but for the purposes of AIDS orphans the point is that all policies adopted by states or donors should ensure that the best interests of all children are paramount and the questions that need to be fully debated are:

- Is it always in the best interest of the child to place children in (over-)extended families where their rights in terms of the ICRC may have no possibility of being recognised and may in all likelihood be violated?
- Is it always against the best interests of the child to place children in some form of institutional care where the rights of children in terms of the ICRC can be recognised?
- How can creative responses to the care of orphans and vulnerable children be created that protect their rights under the ICRC as well as support their identity with and belonging to family and community structures?
In all the debates about care for orphans there is almost no debate about the impact of children when they are placed into homes and families that do not have the resources to care for them and the effect this has emotionally, psychologically and in terms of developmental growth. There is also little discussion about how to ensure that their rights are protected and that they are fully integrated into society. Finally there seems to be very little recognition that placing children into (over-)extended families serves merely to perpetuate and develop poverty, and exaggerate the very conditions that placed children in this position in the beginning. Policies that create the very conditions that make people vulnerable to exploitation, abuse and rights violations need to be the subject of rigorous critique and analysis.

A critical re-examination of institutional care

The current forms of institutional care need to be carefully evaluated and we need to understand where they need to be changed, supported or completely reworked. Dismissing institutional care on the basis of what we know rather than on the basis of what might be is short-sighted and narrow in vision. There are many avenues through which to explore institutional care – through the education department investigating a type of expanded boarding arrangement for school terms while connecting young people to their extended families, to kibbutz-type children’s villages with adult participation and supervision, to extended forms of community housing through the creation of new families, or through the development of adult-supervised cluster housing.

However it is decided that institutional forms of care might be provided, it is crucial to ensure housing, nutrition, clothing, education and health care as well as the strong companionship and support of adults to act in a socialising and security role. The institution of the family would need to be reproduced as far as possible while recognising that in certain instances this may not be possible.

Institutionalised care in whatever way it is envisaged could be a support to child-headed households and in fact it is untenable to even consider leaving children to run households – unless the society recognises their new adult roles and responsibilities and treats them accordingly.

Re-examining institutional care means critiquing the idea that it is better in all cases for young people to be in families.
this will not be the case. It is essential to get a real cost analysis of different possibilities and models of institutionalised care and assess this against the long-term costs of neglect and poverty and discrimination. Looking for new models of institutional care also allows for a critical look at how South Africa could look post-AIDS.

Although the absolute numbers of orphans are important, perhaps more important is the speed at which the numbers are increasing, indicating the mushrooming pressures on society to address the needs of orphaned children.\textsuperscript{189} Under such pressure, some children are encouraged to work to supplement household incomes. Others work out of economic necessity. An already bad situation can be exacerbated by the fact that many of these children can end up in the worst forms of child labour.

The International Labour Organisation has recently sponsored surveys in Tanzania, South Africa, Zambia and Zimbabwe that have confirmed the linkages between HIV and AIDS and orphanhood and the likelihood that a child will work, frequently outside of the household and in conditions that are sexually and economically exploitative and prone to harassment and violence.\textsuperscript{190} AIDS orphans are often found to be neglected and exploited in foster homes.

How does a child head up a household?

Children living in child-headed households may struggle to get births registered, and to get health care treatment, social security and other state mechanisms which can help them. Rules of inheritance in customary law make children vulnerable to being dispossessed of their houses and land. ‘Property grabbing’ by families and communities, who seize the land, cattle, and other assets when household heads die, is linked to the spread of HIV and AIDS across Africa. Simply trying to survive and raise younger siblings creates very real practical problems for primary care-givers who are themselves still undergoing the transition to adulthood.\textsuperscript{191}

The new Children’s Act, part of which came into law in March 2008, has not defined what is meant by the “basic health care services” to which children are entitled, and Hassim \textit{et al.} point out that this concept is also not defined in any government policy. “Because the law does not define what ‘basic’ health care services are, policy-makers, law-makers and service providers are often not clear about what health services should be provided to adults and children to meet this constitutional standard”.\textsuperscript{192}
The problem is further confounded by the fact that children’s health rights are scattered throughout a number of different pieces of legislation, leading to fragmentation and gaps, both in policy formulation and service delivery. Government has not taken the opportunity to ensure a comprehensive and holistic approach to children’s health through the National Health Act [a law which does not treat children as a separate group with separate needs] or the Children’s Act.  

Although the new Children’s Act introduces a number of improvements, a host of challenges and problems remain that impact on the rights of children and young adults, including those who are orphans and head households or who are part of such a household. It is clear that the fundamental rights of children are still not universally enjoyed in South Africa. For example, despite the right to life and the right of all children to basic health care, it is still the case that one child in ten does not survive to its tenth birthday.

Sloth-Nielsen says that of the many constitutional rights being infringed in the context of orphans, children who have been made vulnerable by HIV/AIDS, and children living in child-headed households, the most important is one of the foundational rights of our democracy: the right not to be unfairly discriminated against by reason of one’s birth, race, creed, gender – or age.  

The way in which we think about children – as valuable rather than as vulnerable – should ensure that they all have access to good public health and that public health interventions ensure that their rights are respected and protected. Ensuring that young people are assets we protect should guarantee that they develop good social and legal capital and that they are able to take their rightful place in society – rather than experiencing society as a place that relegates them to the margins.

Provisions in the Constitution for “arrested, detained and accused persons” are the longest and most complex in the Bill of Rights. Hassim et al. suggest that some of the concern over the rights of prisoners and detainees comes from the experience of apartheid when there was wholesale neglect of fundamental human rights in relation to convicts and people held before trial – or without even the intention that they should ever stand trial.  

Thousands were held under laws permitting indefinite detention in solitary confinement and many died in detention. In a number of cases the negligence of health workers
was an important contributing factor to these deaths in detention.

Despite the experiences of the past, however, many members of the public, as well as officials who work with convicts, do not understand that prisoners have rights that are guaranteed in the supreme law.

In the Constitutional Court’s historic case on the death penalty, the court made it clear that while some of a prisoner’s dignity may be impaired through incarceration, prisoners do not lose all their rights on imprisonment. The head of that court, Justice Arthur Chaskalson, said that even though imprisonment is a severe punishment imposed on prisoners, they “nevertheless retain all the rights (emphasis added) to which every person is entitled under the Constitution subject only to limitations imposed by the prison regime”.¹⁹⁶

Thabani Jali, formerly the deputy judge president in KwaZulu-Natal, headed a commission of inquiry into prisons, and commented: “Convicted criminals have for a long time been regarded in South Africa as outlaws. We have chosen to deny their existence and consider them as a form of sub-human species deserving of the consequences of their deeds. This lack of concern has allowed a mentality to take root amongst many correctional officials that prisoners can be treated in any manner without fear of sanction.”

In addition to all the special rights contained in Section 35, prisoners also maintain many other fundamental rights that apply to people outside jail. For example, they have a right to dignity, to have sufficient food and water, to be free from all forms of violence, not to be tortured, and not to be subjected to slavery. Of particular importance in the context of this Review, they have the right to have access to health care services. This right is guaranteed to prisoners in both section 27 (which applies to “everyone”) and in section 35 (2) (which speaks of “everyone who is detained, including every sentenced prisoner”).

The idea that prisoners are owed a duty of care by the government and the Department of Correctional Services (in particular) is also emphasised in the Correctional Services Act of 1998. Regulations issued in terms of this law say that the level of primary health care available in jail must be on the same level as that provided by the state in public-sector clinics.

However, the rights contained in the legislation and the Bill of Rights are not necessarily observed. Their breach
has caused concern among human rights activists as well as great resentment among prisoners – and has led to court action to force their observance. The right to health, in particular, has been the subject of several legal challenges, including cases brought by prisoners with HIV who were not been allowed to access antiretroviral treatment while in jail.

In the first place the enormous overcrowding in jails must inevitably lead to poor conditions. In May 2005, an editorial appeared in the South African Medical Journal on this issue. “Gross overcrowding is the major problem facing the majority of our 240 prisons, which house more than 180 000 prisoners,” the editorial said. “Young men under the age of 30 years represent 60% of the prison population (largely engendered by poverty and joblessness) while women comprise only 2.3%. In several prisons occupancies are well over 200%. This leads to appalling conditions with deprivation of human rights and huge financial costs to the country”.197

Speaking at a conference on prison overcrowding, held in Pretoria during September 2005, Judge Hannes Fagan, a veteran visitor of jails as a member of the Judicial Inspectorate of Prisons, gave his audience some additional figures:

We have dreadful conditions due to overcrowding in most of our prisons. 187 000 prisoners with space for 114 000, i.e. 73 000 too many. Conditions vary. While a few prisons were not overcrowded, most were badly so. An example is Johannesburg Medium B, built to accommodate 1 300, that was housing 4 984 prisoners on 31 January this year.

In April 2003 when I visited Johannesburg Medium A there were cells for 38, holding 101 juveniles. The single toilet in each of those cells had to be used by 101 youngsters, and by 10 am, there was no water for the toilets or to drink. Scabies, chicken pox, TB, HIV/AIDS are rife.198

Hassim et al. point out that responsibility for the health of prisoners lies with the Department of Correctional Services, rather than with the Department of Health. “For many years organisations like the AIDS Law Project argued that this prejudices health care for prisoners because it means that they do not benefit from the same standards of care that exist in the public sector”.199

The Department of Health has been increasingly drawn in over disputes concerning health services for prisoners, particularly as the number of convicts with HIV has escalated, resulting in greater numbers of deaths as well as
legal action over the provision of ART. The situation has deteriorated to such an extent that prisoners are increasingly forced to seek outside help to take their complaints about rights infringements to court.

Referring to medical parole and the problems associated with it, Hassim et al. say that early release on medical grounds is a “bureaucratic and often lengthy process” during which the “condition of many prisoners worsens and some die before their release is approved”.

Among the factors that have led to these delays they list the reluctance by some families to take back a dying prisoner. “This may be worse if the HIV status is known and officials fail to make adequate arrangements for other placements for such prisoners.” Even in cases where staff of correctional services reach the conclusion that the person should be released it would still be necessary for an examination by the district surgeon, a specialist, a social worker and members of the parole board. All this can take weeks – even months. “Parole Board members may not be skilled in assessing complex medical circumstances. Applications are often rejected based upon an incorrect consideration of current and/or previous criminal records and other irrelevant factors, without due consideration of the prisoner’s medical needs.”

**Prisoners living with HIV and AIDS**

Perhaps the case involving prisoners seeking to enforce rights that has most captured public attention in the past few years has been the matter of *EN and others v the Government of South Africa and others*. In this case 15 prisoners with HIV, assisted by the AIDS Law Project, went to court in April 2006 because they had been unable to access ART from prison.

The situation has deteriorated to such an extent that prisoners are increasingly forced to seek outside help to take their complaints about rights infringements to court. The prisoners, all from Westville Prison, just outside Durban, wanted the court to order that the government should remove all the obstacles that were preventing them from accessing ARV therapy “at accredited public health-care facilities”, and to order that they should be provided with ART in accordance with the government’s established “Operational Plan for Comprehensive HIV and AIDS Care”.

The application came as no surprise to the government: between October 2005 and March 2006 there had been lengthy but ultimately fruitless meetings and exchanges of correspondence between the AIDS Law Project and the prison authorities on the issues at stake. More than 110 prisoners had died of AIDS in Westville Prison during the year prior to the application. Prisoners in the jail were
denied ART and had no treatment for opportunistic diseases associated with HIV such as tuberculosis and thrush. Some HIV-positive prisoners in Westville Prison at the time of the application were unable to walk, wash or even eat without help.

Although the judge granted the order, this was followed by further delaying tactics from the state. In March 2007, a year after the case first came to court, and just days before the matter was due back before a judge, the two sides were involving in talks about settling out of court: the state had still not accepted the implication of its responsibilities in relation to providing prisoners with ART.

At the time of writing no settlement or agreement had been reached with official representatives of the Departments of Correctional Services and of Health, well over two years after the case first went to court. The ongoing delays and failure to resolve the important issues at stake meant that the AIDS Law Project and their clients would have to reconsider the way forward, including the possibility of going back to court again as there were several matters that had been left hanging in the hope that they could be settled.

While the situation has greatly improved in the wake of the Westville case – antiretrovirals are now available at certain prisons and at others prisoners are to access their therapy via the public health system – there is still an enormous problem in relation to questions such as testing and nutrition.

Lawyers for the state say the only question raised by the case is “the ARV pills”. We say there is far more involved. If prisoners who are living with HIV aren’t tested to check their CD4 count, how will they know when to start “the pills”? And they would have to have this check regularly and often to monitor when their count drops to the level that they must start taking ARV therapy.

“It’s also about nutrition: people on antiretroviral therapy must take their tablets regularly, at the same time, morning and evening. It’s not advisable to take the medication without a proper meal – and yet there is no evening meal in prison. Even more of a problem, however, is the evening medication for those taking drugs for AIDS-related TB. It can be harmful and they won’t get the benefit of the drugs”.

Several of the applicants in the original Westville application have since died, including one who started on ARV treatment three weeks before he died. His lawyers discovered that he would have been eligible for treatment three and half years before he was permitted to begin,
and they asked for an investigation and a report on the situation. That report was filed with the department in 2006, and the lawyers have tried since then to get a copy of it.

The whole Westville saga with all its many ramifications illustrates the difficulties of ensuring respect for the rights of prisoners, even for their health rights. Although they have the right of access to health care services in terms of section 27 and to adequate medical treatment in terms of section 35, their lawyers have still – at the time of writing it has been two years and two months after bringing the first application – not been able to ensure that these rights are properly observed.

Prisoners who took part in the application or who were supportive of it have been victimised and their lives made quite miserable. Independent doctors wanted to come in and check on the patients and their progress. The authorities made it almost impossible. The victimising of people who took legal action, and the attempts to prevent private medical practitioners from having access to prisoners, is a further infringement of the rights of convicts.

Prisoners find it exceptionally difficult to contact a lawyer to help them on issues of health, and the right of access to court is infringed when people can’t reach a lawyer. All have a right, in terms of the basic values and principles governing public administration, to accountable and transparent administration – but that is clearly lacking for prisoners.

Singh and Maseko say it is a truism that prisoners like other people are entitled to good health. “The WHO constitution is explicit that: the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition. The stance by WHO to uphold and protect prisoners’ rights to health care services is not only reflected in the preamble of its constitution but also in terms of the guidelines drafted for the treatment of prisoners. Prisoners have a right to receive health care equivalent to that available in the community without discrimination (because) of their legal status”.

The two authors go on to examine international human rights law and they find evidence that the health of prisoners is widely protected as a right.
Refugees, asylum seekers and undocumented migrants

Remember me
the woman who slept alone in the field
with nothing but a torn wet blanket
to cover her shame
far away from home
across many rivers
away from her native land

the woman with shattered dreams
who longs for a home.
– Mary Magdelene Yuin Tal (from: Living on the Fence, poems by women who are refugees from various countries in Africa)

The newspaper headlines say it all. Referring to a mob attack on foreigners living in Johannesburg’s Alexandra township over the mid-May weekend of 2008, they ask: Is this the new South Africa?
Three people were immediately known to have been killed in the unprovoked attack, one of them a local man who refused to participate in the looting, rapes and assaults, as well as the burning of shops and homes. The targets appeared to have been mainly Zimbabweans, although other foreigners were also victims of the crowd violence. Forty people were injured, with 39 people arrested from among the many who allegedly attacked their neighbours using iron bars, sticks, guns, knives and stones. In the weeks that followed many more people were attacked and killed. Thousands were displaced from their homes and sought housing in temporary and inadequate shelters set up by the government.

Loren Landau, the director of the Forced Migration Studies Programme at Wits University, said that xenophobic attacks were becoming increasingly frequent, against the backdrop of worsening social and economic pressures faced by poor South Africans. “These are tumultuous times,” he said. “There is a lot of uncertainty and disillusionment among South Africans, coupled with increases in food, fuel and electricity prices ....”

He said most illegal immigrants moved into impoverished neighbourhoods and informal settlements. “South Africans were promised some sort of rebirth after 1994 and they are still waiting for the benefits. They now blame foreigners for their frustrated dreams,” Landau said. “The poor feel marginalised, neglected and worse off than before. In the absence of the government addressing their legitimate concerns, they are looking for scapegoats”.

Unfortunately the mid-May attacks were far from isolated. The Consortium for Refugees and Migrants in South Africa (CoRMSA) kept account of such events, and in the wake of the Alexandra problems in May 2008, the organisation issued a statement that included a record of 13 similar attacks on foreigners in the six months from December 2007 in Gauteng, North West, the Eastern Cape and the Western Cape.209

The Consortium said that even though many individuals and groups in civil society had urged that action should be taken, there had been no coordinated response or strategy by government to address mob violence against foreigners. It now required “the leadership of the Presidency to set up an inter-departmental task team to address this ongoing crisis in the country,” CoRMSA said. “These are hate crimes and such violence against non-nationals cannot be treated as isolated incidents, but rather as a national crisis. There is thus a need for a comprehensive national strategy to combat and address xenophobic violence which involves multiple
government departments and includes a strategy to provide assistance to those displaced by xenophobic violence. Such a strategy will also need to provide clear guidelines to the South African Police Services (SAPS) so that a consistent approach ensuring the safety of all is adopted when such incidents arise”.210

“Important elements of such a strategy would include:

• Addressing the source of conflict involving non-nationals in communities rather than deporting non-nationals, thus facilitating a form of ‘ethnic cleansing’.
• Strengthening mechanisms of conflict prevention and resolution in communities and empower local government to deal with such conflicts.
• Mechanisms to reintegrate those displaced by xenophobic violence back into the communities, including structures to guarantee their safety on return.
• Support the inclusion of non-nationals in community structures such as community policing forums so that such conflicts can be addressed at a local level before they escalate.
• Engaging with civil society to jointly find solutions to some of the causal factors of xenophobic violence.
• Passing legislation targeting ‘hate crimes’ to serve as a powerful deterrent”.211

These are simply the most overt attacks and threats that refugees, asylum seekers and undocumented persons face in South Africa: there are many other difficulties, attacks on and threats to their safety, their dignity – and their rights. Attacks on their rights do not only come from their township neighbours, armed with sticks and guns, but also from government officials who, whether from ignorance or for some other reason, act in a way that undermines the dignity and the rights of vulnerable non-nationals.

In March 2008, a number of non-governmental organisations whose work in some way involves the right to health, formulated a joint submission to the South African National AIDS Council plenary. Their document was entitled “Vulnerable groups: refugees, asylum seekers, and undocumented persons – the health situation of vulnerable groups in South Africa”.

Their joint submission cites government policy and directives, issued in April and September 2007 by the national Department of Health, that all refugees and asylum seekers, with or without a permit, “shall be exempt from paying for services related to the provision of diagnostic services as well as antiretroviral medicines”. These directives were not communicated properly (if at all) to health care workers or senior public health officials, and in particular the heads of clinics and hospitals. As a result, “We have
found that our protective legal framework is not being applied uniformly. Public hospitals, clinics and other institutions appear to be unilaterally creating policies which deny refugees access to health care services, violate existing legal and human rights obligations, and undermine the objectives of the National Strategic Plan.”213

The submission says that both the Constitution and the Refugee Act of 1998 “guarantee and recognise the right of ‘everyone’ to access health care, thus including refugees, asylum seekers and undocumented persons. The right of detainees to receive medical treatment is also contained in section 35(2)(e) of the Constitution. The right to enjoy the highest attainable standard of health is also guaranteed by international law. This right also imposes an obligation on states such as South Africa to take necessary steps for the prevention, treatment and control of the HIV epidemic and other diseases. In meeting this obligation, states should ensure that appropriate goods, services and information for the prevention and treatment of STDs, including HIV/AIDS, are available and accessible to all those living in its country”.214

According to the National Strategic Plan, certain groups, including refugees, asylum seekers and foreign migrants, are identified as “marginalised groups necessitating proper policy interventions for HIV prevention, treatment, and support”. And yet state officials are denying these very groups their rights to the HIV assistance they need.

The organisations have been involved in research in the greater Johannesburg metropolitan area concerning the particular experiences of refugees and asylum seekers in search of ART through the public sector. Refugees and asylum seekers are charged excessive fees (when they should not be charged anything at all). They often don’t know how to enforce their rights to health care, or perhaps lack the competence or emotional strength to do so. They are also often refused care on the basis that they don’t have proper South African identification (although the directives referred to earlier make it clear that they do not need such identification).

“Instead of referring patients to an appropriate ARV treatment site as is legally required, local government clinics increasingly refer refugees, asylum seekers and other non-citizens out of the public sector and directly into the already overburdened and under-resourced non-governmental sector in order to access ART. The resulting parallel provision of ART through both the public and NGO health sectors fails to integrate treatment routes for patients without reasonable justification and violates the objectives of the NSP and the NDoH’s policy directives. Budgetary excuses for denying access to ART are also frequently
cited in the case of refugees and asylum seekers. Health care workers are also known to claim that a facility does not have the budget to look after ‘additional’ patients who happen to be non-South African”. 215

“If donor-sponsored community treatment programmes are unable to address the demand for health services of non-citizens then patients who are living with HIV and/or TB are unable to access timely treatment. This will lead to further public health problems, including unnecessary suffering and death, and contribute to the further spread of TB”. 216

A second area where the NGOs complain that the health rights of vulnerable foreigners is unlawfully denied or compromised is at the places where they must wait to access their documentation. Their submission speaks of the thousands of people who queue every day outside refugee reception centres run by the Department of Home Affairs in several parts of South Africa.

Even worse problems were experienced at detention centres. According to the submission, two of the five such centres represented “the most egregious human rights abuse”, including particularly severe public health problems for refugees, asylum seekers and undocumented persons. A major problem was that South Africa did not have an independent body that monitored deportations from the detention camps. This meant that no independent monitoring of conditions was taking place, for example at Lindela Repatriation Centre, even though human rights advocates denounced the conditions at it right from its opening in 1998. Every day there were reports that hundreds of people were “arbitrarily deported from Lindela back to their country of origin – including places that are internationally recognised as disaster areas, engaged in ongoing civil conflict, and/or politically repressive. Access to the facility by the lawyers and doctors of those detained is frequently denied by the administration”. 217

Health care workers are also known to claim that a facility does not have the budget to look after ‘additional’ patients who happen to be non-South African.

The conditions at detention centres such as Lindela are worrying from a public health perspective. The implications of overcrowding, poor sanitary conditions, lack of regular access and visits by health care workers and/or observers and the clearly limited capacity of Lindela and other detention centres to provide health services itself results in serious public health problems for South Africa including an immediate and ongoing risk of TB. 218

But alarming though it is in the apparently unconstitutional practices it describes, this submission at least speaks of a government policy that recognises the right to health of refugees, asylum seekers and undocumented people,
and thus their right to access health services, including HIV treatment.

Another submission also made in March 2008, by the AIDS Law Project and the Treatment Action Campaign, shows an even more alarming situation in relation to the health rights of vulnerable foreigners. The organisations object to the Refugees Amendment Bill, proposed to Parliament, which, far from recognising and seeking to protect the health rights of this group of vulnerable people, would remove the “right to health services” in the existing Refugee Act.219

In terms of the proposed amendment, Section 27 (g) of the Refugee Act (1998) which says that refugees would be “entitled to the same basic health services and basic primary education which the inhabitants of the Republic receive from time to time,” would be deleted. There would be a further change to the existing Section 27. It now says that “A refugee ... enjoys full legal protection, which includes the rights set out in Chapter 2 of the Constitution [the Bill of Rights] and the right to remain in the Republic in accordance with the provisions of this Act.” If the amendment is passed, however, it will read, “A refugee is entitled to ... full legal protection, which includes the rights set out in Chapter 2 of the Constitution of the Republic of South Africa, 1996 (except those rights that apply only to citizens)”.220

The problem with this proposed change is that if the reference to health rights is removed from the new version of the Act it would “eliminate the explicit right to access health services for refugees and asylum seekers and create uncertainty in respect of rights that ‘apply only to citizens’”.221

“Given the widespread denial of health services coupled with uncertainty about the right to access to health services by refugees and asylum seekers ... we support an explicit reference to the ‘right to health’ – it is warranted and should be retained. It is therefore imperative that a clear and unambiguous right to access health care services in line with established government policy be inserted in the Bill to protect refugees and asylum seekers”.222

Another alarming proposal is that Section 6 of the existing Act should be removed. This is the section that expressly incorporates international treaties and declarations into the interpretation of the Act. These treaties and declarations are part of the international legal obligation to protect at a minimum a wide set of rights.
Many of these rights are being breached already, even though Section 6 says that they must apply in interpretation of the Act. For example, conditions at the detention centres are not independently monitored to ensure that they comply with the constitutional right to access health care services. This is because there is no specific provision that says such monitoring must take place unhindered. In themselves the conditions at the centres, because they are so unhygienic, put the health rights of every person there at risk.

Overcrowded, unsanitary conditions such as are found at the centres inevitably increase the possibility of the spread of disease, including multi-drug resistant (MDR) TB. Obviously, therefore, if the health rights of non-nationals are flouted in this way, the rights of the citizens of South Africa are also put at severe risk.

In June 2006, Zonke Majodina, the deputy chairman of the Human Rights Commission, said that the xenophobia seen in South Africa was typical of a society in contradiction with itself, resisting diversity not only internally but also externally. Majodina said it was urgent for South Africa to tackle its failure to protect the rights of refugees.

South Africa had an excellent legal and policy framework, Majodina said. The Refugee Act of 1998 was testimony to the good intentions our policy-makers had when they incorporated human rights norms into the regulatory framework governing issues of forced migration. But in reality, even after passing the status-determination test, refugees still did not enjoy even the most basic human rights, such as freedom of movement, access to services such as health-care, and access to education for their children.

The extremely xenophobic attitudes of the South African public add to the plight of many refugees. In addition to the possibility of being thrown into police cells and being unlawfully detained by our law enforcement agencies, refugees have to be constantly on the alert because they are easy prey to people in the street. Violent attacks on refugees at community level have become a frequent occurrence all over the country.224
CONCLUSION

This chapter has looked at how the rights of some of the most vulnerable groups in our society are constantly flouted. Children, prisoners and foreigners are particularly vulnerable because they cannot intervene when the community or government officials trample on their rights. When the health rights of any group are compromised its members suffer, but members of the rest of society also face a strongly increased risk to their own health too.

When the rights of vulnerable groups are threatened, it impacts on all of South Africa. We become less concerned about the rule of law, less sensitive to the needs of others, and less scrupulous about observing the rights to which we are all entitled. The human rights health of the whole of our society suffers. And as a result, “We the people” will have failed the test posed in the preamble of our Constitution, to “heal the divisions of the past and establish a society based on democratic values, social justice and fundamental human rights ... and “to improve the quality of life of all citizens”.”
Chapter six: A coercive balancing act: tuberculosis

While it is encouraging that the South African government invited the World Health Organisation to an October 2006 meeting on the emerging crisis, it is worth noting that neither party raised the human rights and ethical dimensions of controlling the outbreak.

– Singh et al., writing about the current South African epidemic of drug-resistant tuberculosis

The Patients’ charter for tuberculosis care (the Charter) (available at www.csa.za.org under ‘Downloads’), outlines the rights and responsibilities of people with tuberculosis (TB). It seeks to empower people with the disease and their communities. Initiated and developed by patients from around the world, the Charter makes the relationship with health care providers a mutually beneficial one. The Charter sets out the ways in which patients, the community, health providers (both private and public), and governments can work as partners in a positive and open relationship with a view to improving TB care and enhancing the effectiveness of the health-care process. It allows for all parties to be held more accountable to each other, fostering mutual interaction and a ‘positive partnership’.

Developed in tandem with the International standards for tuberculosis care to promote a ‘patient-centered’ approach, the Charter bears in mind the principles on health and human rights of the United Nations, UNESCO, WHO and the Council of Europe, as well as other local and national charters and conventions, including the United Nations CESCR General Comment 14 on the right to health, the WHO Ottawa Charter on health promotion, the Council of Europe Convention for the Protection of Human Rights and Dignity (biology and medicine), and the UNESCO Universal Draft Declaration on Bioethics and Human Rights.

The Patients’ Charter for Tuberculosis Care invokes the principle of the Greater Involvement of People with Tuberculosis (GIPT). This affirms that the empowerment of people with the disease is the catalyst for effective collaboration with health providers and authorities and is essential to victory in the fight to stop TB. The Charter, the first global
‘patient-powered’ standard for care, is a co-operative tool, forged from common cause, for the entire TB community.

TB is a curable disease but it kills millions in the developing world. As such it is a glaring example of global inequalities in access to health care. Drugs to fight TB have been in existence for 50 years, and in rich countries deaths from TB are rare. Yet TB kills 5 000 people every day, nearly 2 million people per year. More than 2 billion people, almost one third of the world’s population, are infected with the microbes that cause TB.

In recent years, the TB epidemic has intensified alongside another global plague of the poor: HIV/AIDS. People whose immune systems have been weakened by HIV are particularly vulnerable to contracting and dying from TB. The spread of HIV has led to millions of new TB infections – particularly in sub-Saharan Africa – making TB the leading cause of death for people infected with HIV/AIDS.

Many writers and medical scientists who discuss South Africa’s health problems speak of the ‘twin epidemics’: HIV/AIDS and TB. One often appears to piggy-back on the other, giving further, often fatal, impetus to both. They are both epidemics that flourish particularly well under conditions of poverty and inadequate nutrition.

As Singh et al. put it, “In the modern era, tuberculosis is recognised as a disease that preys upon social disadvantage”.

There is another way in which the two are related: they seem to be mirror images of each other in terms of the suggested manner that they should be addressed. If you read conventional proposals for treating patients with multidrug-resistant TB (MDR TB) and the even more dangerous and difficult to treat extensive drug-resistant TB (XDR TB), you could well think you were reading documents from the early days of the HIV epidemic, when some health officials and politicians recommended indefinite isolation or even detention of the infected, until death if necessary. The overarching rationale given was the same in the case of both HIV and drug-resistant TB: the health of the community necessarily requires the isolation of those infected, and the right to health of the greater community must override the individual liberty rights of the individual.

A World Health Organization policy statement entitled ‘WHO guidelines on human rights and involuntary detention for XDR-TB control’ serves as a good example of this. It states:
...if a patient wilfully refuses treatment and, as a result, is a danger to the public, the serious threat posed by XDR-TB means that limiting that individual’s human rights may be necessary to protect the wider public. Therefore, interference with freedom of movement when instituting quarantine or isolation for a communicable disease such as MDR-TB and XDR-TB may be necessary for the public good, and could be considered legitimate under international human rights law.\textsuperscript{228}

The euphemistic way in which the title of this document attempts to make the term ‘quarantine’ more palatable by calling it ‘involuntary detention’ is also telling. Given the growing appeal of human rights discourse, it would perhaps not be surprising if ‘involuntary detention’ becomes ‘splendid isolation’ in the not too distant future.

Yet just as this approach proved in the case of HIV/AIDS to be unhelpful, unscientific, impossible to implement and counter-productive, so there are medical experts who believe the coercive approach to drug-resistant TB preferred by many governments and health departments should be ditched in favour of a treatment method that actually works and that does so without compromising human rights.

Just as AIDS was met by delay and denialism from government in South Africa, so the serious outbreak of drug-resistant TB has not been met with the alacrity it requires. In fact the development of the epidemic into the nightmare it has become was made possible in the first place because of inadequate official responses both to HIV and to TB which, even in its drug-sensitive form, has long been a problem. In other words, if the government had acted with clear and committed intent to eradicate TB at the time when drug-resistant forms were rare or even unknown, the situation would not have reached its present crisis.

As Singh et al. warn in a paper entitled ‘XDR-TB in SA: no time for denial or complacency’, “The South African government’s initial lethargic reaction to the crisis and uncertainty amongst South African health professionals concerning the ethical, social, and human rights implications of effectively tackling this outbreak highlight the urgent need to address these issues lest doubt and inaction spawn a full-blown XDR-TB epidemic in South Africa and beyond”.\textsuperscript{229}

World-wide estimates of the growth of the problem are alarming. In their April 2008 newsletter WHO and Stop TB Partnership recorded the publication by WHO in February of the fourth report \textit{Anti-tuberculosis drug resistance}
in the world. It records the highest rates ever recorded of TB resistant to standard drug treatments. “Estimates from the data (collected between 2002 and 2007 in 83 countries and territories) indicate nearly half a million cases of multi-drug resistant TB (MDR-TB) emerged in 2006, or about 5% of the nine million new TB cases annually”.230

South African figures are also alarming. In its strategic plan for TB in South Africa for 2007-2011, the Department of Health has included several tables showing the incidence of MDR- and XDR-TB in the nine provinces. Between January 2004 and April 2007 there were more than 11 000 laboratory-confirmed MDR cases across the country. Of these, a significantly high proportion, 36%, came from the Western Cape. And yet, as the strategic plan points out, this province “has arguably the best TB control programme in the country”.231 Why then is the figure so high in the Western Cape? The report suggests that perhaps health workers in this province have a better developed sense of suspicion of MDR-TB, enabling them intuitively to sense when a patient should be checked for this form of the disease.

If that is the correct interpretation of the figures, however, it means that the other provinces could well be under-reporting because the extent of MDR-TB is under-diagnosed. What makes this interpretation all the more likely, and “highly worrying”,232 is that Mpumalanga, where TB control programmes are known not to be functionally properly, has registered a decline in the proportion of South African MDR-TB cases diagnosed over the three years 2004 to 2006.

Although research based at the Church of Scotland Hospital (Tugela Ferry) in KwaZulu-Natal shocked the health community in 2006 with its high figures of XDR-TB prevalence, it was not a new phenomenon. Statistics from the Department of Health show that XDR-TB had been recorded since 2004. Again, there is a significant discrepancy between the provinces, coupled with a sharp increase in the total numbers for South Africa from 2006 onwards. While KwaZulu-Natal heads the list (at 65% of the total number of cases), it seems that other provinces are under-detecting the prevalence of XDR-TB.

Even at the presently reported rate, however, the view of the Department of Health is that the situation is grave: “The extent of XDR-TB and the magnitude of the problem have serious public health consequences, not only for South Africa, but for the whole African region, as well as globally”.233
Now that the serious public health problem posed by drug-resistant TB has been identified, what is happening on the ground?

The answer is not a happy one for any of the parties involved. This is largely a story of enforced isolation and of patients angry – even desperate – at their treatment. In late March 2008, readers of the *New York Times* had a glimpse inside what a recovered TB patient in South Africa was later to call “a response from hell”. Under the heading, “TB patients chafe under lockdown in South Africa”, the *New York Times* took readers to Port Elizabeth’s Jose Pearson TB Hospital: a prison for the sick, they called it:

“We’re being held here like prisoners, but we didn’t commit a crime,” Siyasanga Lukas, 20, who has been here since 2006, said before escaping last week. “I’ve seen people die and die and die. The only discharge you get from this place is to the mortuary.”

Struggling to contain a dangerous epidemic of XDR-TB, the South African government’s policy is to hospitalise those unlucky enough to have the disease until they are no longer infectious. Hospitals in two of the three provinces with the most cases – here in the Eastern Cape, as well as in the Western Cape – have sought court orders to compel the return of runaways.

The public health threat is grave. The disease spreads through the air when patients cough and sneeze. It is resistant to the most effective drugs. And in South Africa, where resistant strains of TB have reached every province and prey on those whose immune systems are weakened by AIDS, it will kill many, if not most, of those who contract it.

As XDR TB rapidly emerges as a global threat to public health – one found in 45 countries – South Africa is grappling with a sticky ethical problem: how to balance the liberty of individual patients against the need to protect society.
Most other countries are now treating drug-resistant TB on a voluntary basis, public health experts say. But health officials in South Africa contend that the best way to protect society is to isolate patients in TB hospitals. Infected people cannot be relied on to avoid public places, they say. And treating people in their homes has serious risks: patients from rural areas often live in windowless shacks where families sleep jammed into a single room – ideal conditions for spreading the disease.

Other public health experts say that overcrowded, poorly ventilated hospitals have themselves been a driving force in spreading the disease in South Africa. The public would be safer if patients were treated at home, they say, with regular monitoring by health workers and contagion-control measures for the family. Locking up the sick until death will also discourage those with undiagnosed cases from coming forward, most likely driving the epidemic underground.

Further complicating matters, South Africa’s provinces have taken different approaches to deciding how long to hospitalise people with XDR-TB. In KwaZulu-Natal, the other province with the most cases, the main hospital is discharging patients after six months of treatment, even if they remain infectious, to make room for new patients who have a better chance of being cured. The province is rapidly adding beds, part of a national expansion of hospital capacity for XDR-TB.

On the whole the South African public cannot understand the complexity of the issues involved. Stories about ‘absconding’ patients are carried in the media as something frightening because the ‘patients on the run’ could infect them and make them die. Often the ‘recapture’ of the ‘TB-criminals’ is reported with the same glee and relief as when dangerous awaiting-trial suspects are re-arrested after managing to escape.

If the policy sanctioned and implemented by the doctors in charge of many South African TB hospitals is isolation behind walls and razor wire, indefinite detention under armed guard until death if necessary, what does the wider medical profession have to say about it? And what are the human rights implications of such measures?

During a presentation to the South African TB Conference in July of 2008 the executive director of the AIDS Law Project, Mark Heywood, summarised the current situation in the evocative phrase “squabbling while Rome burns – letting TB happen.”234

The South African Medical Research Council has tried to advise its constituency about the conflicts and dilemmas
WE TEST FOR TB:

SPUTUM TEST

Cough

Spit

LABORATORY

© Schalk van Zuydam / AP Photo / Models passed
involved, and to make them more aware of the complexities. In a special policy brief the council looks at the stark dilemma facing the medical community – and the rest of us. The policy brief describes the emergence of MDR and XDR-TB as “essentially a man-made problem”; it emerges in a community because patients with conventional TB are given inappropriate or ineffective treatment, thus allowing “naturally-occurring resistant TB bacteria to survive and multiply”. Even before MDR- and XDR-TB, South Africa had one of the worst TB epidemics in the world. Now the epidemic has dramatically worsened the situation, bringing new suffering as well as new legal and ethical dilemmas.

The council frames the situation as a conflict between public anxiety on the one hand, and the Constitution on the other, another of the balancing acts between fear and good, between public health and human rights, but notes that both approaches have their problems.

“Public anxiety, coupled with the risk that XDR-TB may rise to epidemic levels in SA, is putting increased pressure on government and public health authorities for quarantine of patients and coercive measures to curtail the spread of XDR-TB.” The ‘dual stigma’ associated with both TB and HIV is now intensified because XDR-TB is seen as so much worse (than ‘conventional’ TB). The strongly negative social attitude to XDR-TB therefore poses a real risk of driving the XDR-TB problem underground, especially if isolation measures are coercive.

There is legislation in South Africa that allows for public health interventions “in order to contain infectious diseases that constitute a threat to public well-being”. This, the council points out, “provides a legal framework against which health authorities may invoke their regulatory responsibility to effectively address public health issues”.

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The grave public health threat of XDR-TB would, therefore, provide a legal basis for governmental intervention in decision-making of an individual’s health care.” At this point the council raises the question of South Africa’s Supreme Law – the Constitution – and whether coercive action of the type apparently permitted in the individual legislation and contemplated (and practised) by doctors at some TB hospitals, would be permissible.

The council’s ultimate conclusion is, at best, inconclusive and the advice it offers ambiguous: “The utilitarian approach, advocating that government policies be directed to provide for the greatest good to the largest component of the population, certainly makes sense from a public health perspective. Nevertheless, the humanitarian approach in
which patient dignity, equality and freedom constitute core values, also needs to be taken into account for management of XDR-TB.”

In another briefing document however, the Medical Research Council tackles the question more directly: “In order to protect communities, MDR-TB must be effectively treated, and patients with active MDR-TB must be prevented from infecting others. But doing so can violate the human rights of patients as protected in the Constitution. The responsibilities and powers conferred upon public health practitioners by health legislation need to be balanced with the rights of patients.”

The coercive approach of some hospitals and authorities, on the basis of which people are detained indefinitely and have been rounded up if they ‘escape’, has not been tested to see if it is constitutionally acceptable. No such tests appear to be in the offing. One of the issues raised by the council is that enforced hospitalisation or quarantine of patients with XDR-TB is only justifiable as a last resort, after all reasonable voluntary measures to isolate individual patients have failed. And coercive measures such as these which restrict the rights of patients will not pass legal scrutiny if it cannot be shown that all the criteria of the Siracusa Principles have been met, and that the envisaged restrictions are “limited in duration and subject to review and appeal.” These criteria are:

- the restriction is provided for and carried out in accordance with the law
- the restriction is in the interest of a legitimate objective of general interest
- the restriction is strictly necessary in a democratic society to achieve the objective
- there are no less intrusive and restrictive means available to reach the same objective, and
- the restriction is based on scientific evidence and not drafted or imposed arbitrarily, ie. in an unreasonable or otherwise discriminatory manner.

The Siracusa Principles cited by the Council are particularly important because they are similar to the tests that the Constitutional Court would invoke should a case involving enforced hospitalisation of drug-resistant TB patients come before it.

An important statement of the position in favour of isolating patients with drug-resistant TB to reduce the risk of infection spreading, is made by Singh and his colleagues in their January 2007 paper, “XDR-TB in South Africa: No time for denial or complacency”. It is a nuanced position, but one which ultimately makes no apology for coming down on the side of indefinite involuntary hospital isolation for certain patients with drug-resistant TB. The
authors begin by recalling that WHO urged health authorities around the world to respond to drug-resistant TB with “a response ... akin to recent global efforts to control severe acute respiratory syndrome (Sars) and bird flu”.

Despite that call, however, the South African government was slow to respond. In this South Africa is not alone, for as Singh comments, “[I]t could be said that the emergence of MDR-TB itself is evidence of the systematic failure of the global community to tackle a curable disease”.

According to the South African Medical Research Council, about half of adults in South Africa with active TB are cured each year, compared with 80% in countries with better resources. Nationally, about 15% of patients default on the first-line six-month treatment, while almost a third of patients default on second-line treatment. The emergence of drug-resistant TB is an indicator of the poor implementation of South Africa’s TB programme.

TB is recognised today as a disease that flourishes on social disadvantage. At least 10 million South Africans receive some kind of social welfare and because of high unemployment, these grants are often the only income of many families. However, current government policy stipulates that those who are hospitalised at state expense lose their social welfare benefits for the duration of their hospitalisation.

“Faced with the prospect of being deprived of their gainful employment and/or having their welfare benefits suspended for the duration of hospitalisation – which in the case of MDR-TB or XDR-TB could last 18-24 months – many MDR-TB patients opt not to stay in hospitals ... Instead, understandably, these highly infectious individuals fail to receive appropriate therapy and are likely to default on adherence. They mix broadly in society among non-infected individuals ... In so doing, they pose a significant public health risk to their families, co-workers, local community, and the wider public they encounter”.

The authors make another controversial call: patients with XDR should take first priority when space is allocated in hospitals – trumping even HIV patients – because of how easily the disease is spread. They note that most hospital beds are occupied by people battling infections associated with HIV, so that there is limited space for those with drug-resistant TB.

Moving to the issue of the human rights and ethical issues raised by strategies to contain TB, Singh et al. say the global community must come to terms with “the extent to which judiciously sanctioned restrictive measures should
be employed to bring about control of what could develop into a lethal global pandemic“.

Diagnosis of MDR-TB and XDR-TB can take several weeks, so what should happen to patients who might be suspected of having a drug-resistant form of TB, while they wait for the results? Once it is confirmed that patients have MDR or XDR-TB, Singh et al. say “there are questions about how long and how closely their clinical status should be monitored and under what conditions. Ideally, patients suspected of having TB should be isolated in an acute infectious diseases setting”. WHO guidelines recognise that this strategy is not possible in resource-constrained environments. It recommends that persons with MDR-TB voluntarily refrain from mixing with the general public and with those who are susceptible to infection. However, the emergence of XDR-TB shows that the WHO strategy of allowing the patient to assume responsibility for mixing with the general public may be ineffectual.

Involuntary detention may be necessary to assure isolation and prevent infected individuals spreading infection. However, South African officials have raised human rights concerns about dealing with the country’s XDR-TB and MDR-TB outbreaks, although they have conceded that forcible treatment may be a viable option in tackling the outbreak. Health workers and human rights advocates in South Africa and elsewhere need to be reminded that although a country’s Bill of Rights may bestow a range of human rights on individuals, these rights can usually be restricted if doing so is reasonable and justifiable. The courts can order involuntary confinement, hospitalisation and treatment, if doing so is in the public interest. However, this option should only be used if non-coercive measures have failed.

South African officials have raised human rights concerns about dealing with the country’s XDR-TB and MDR-TB outbreaks, although they have conceded that forcible treatment may be a viable option in tackling the outbreak.

Singh et al. suggest: “Questions also remain about how authorities should deal with patients with MDR-TB whom treatment has failed to cure, as well as patients with XDR-TB in whom cure is unlikely as few active drugs remain. While isolating such patients until they die – which in the case of the slightly less deadly MDR-TB could be years – has been described as ‘ethically questionable and impractical’, this option may, of necessity, need to be countenanced.”

Singh et al.’s paper recalls that the people whom it is proposed to isolate indefinitely – until death in some cases – have committed no crime. The authorities who want to lock them up should therefore treat them “humanely”, they say, and provide them with “decent living conditions“.
because the curtailment of their liberty “is more for a collective good than for their own”.

“Although such an approach might interfere with the patient’s right to autonomy and will undoubtedly have human rights implications, such measures are reasonable and justifiable, and must be seen in a utilitarian perspective. Ultimately in such crises, the interests of public health must prevail over the rights of the individual.”

Interestingly, one of the foremost proponents of dealing with MDR- and XDR-TB through non-coercive means is Dr Tony Moll, chief medical officer of the Church of Scotland Hospital at Tugela Ferry. Moll originally discovered the large number of cases of XDR-TB in KwaZulu-Natal (available at www.csa.za.org under ‘Downloads’). In an extended discussion with Moll for this Review, he said that initially his hospital had followed the conventional route of dispatching patients to King George V Hospital in Durban, the referral hospital to which hospitals in outlying areas send patients with drug-resistant TB.

King George V Hospital soon became overwhelmed by the number of cases of drug-resistant TB referred to it and couldn’t cope any more. Tony Moll says, “We’d send people to King George to be initiated into their treatment, and though by rights they should have spent six months at that hospital in Durban, they were very often back with us in Tugela Ferry that same evening.”

Moll and his staff decided to try a new system of treating patients infected with drug-resistant TB. Instead of sending them to Durban they were treated in their homes. Every weekday five injection teams went out into the areas that the hospital served. As patients progressed, they no longer needed daily injections but took medication instead, so the patient lists constantly changed and the injection teams did not necessarily see everyone who had XDR- or MDR-TB every day.

“If a patient stays at his own home and gets visits there every day we are finding adherence much better and the defaulter’s much less”, says Tony Moll. “There is far less transmission in the communities than there is in a hospital,” he suggests. “We have followed up hundreds of people with MDR- and XDR-TB and we’ve done extensive follow-up screening. What we have found is that the spread to household contacts is very small – less than 2%. However, we know for sure that the XDR epidemic is spread at hospitals. Most people who have this form of TB caught it in a hospital when they were there for something else”.
Tony Moll conceded that there could be problems when someone with drug-resistant TB shares a home with someone who is HIV positive and whose immune system is therefore weak. “We give guidelines to the people in the house that, if followed, will dramatically reduce the likelihood of infection for family members”.

Another factor considered by Tony Moll and his colleagues in deciding to continue their home-based treatment of patients with drug-resistant TB is this: studies going back many years have shown that by the time a person with TB eventually reaches a hospital and is diagnosed, those contacts of the person with TB who would have contracted TB have already got it. So sending patients back home won’t make much difference.

Another consideration of Tony Moll and his colleagues is that the patients with MDR and XDR whom they see and identify are just a fraction of the total numbers involved. What then would be the point in pursuing punitive, coercive measures against those patients whom they are able to locate, while the majority of those infected continue to live and work in the community? In KwaZulu-Natal treatment outcomes using conventional coercive methods of isolation have been very poor. He asserts that using coercive methods drives the disease further underground and attaches huge fear and stigma to it.

“I would say that treating people at home makes economic sense (it costs less), makes clinical sense (in that the outcomes are far better), makes social sense (in that families are happier and more supportive) and it makes transmission sense – given all that we know about how quickly drug-resistant TB moves between people in a hospital setting, there’s no doubt that this is a far better option for everyone involved.”

On 29 April 2008 NP Nkonyeni, KwaZulu-Natal MEC for Health, made the following statements in his budget speech:

> Using coercive methods drives the disease further underground and attaches huge fear and stigma to it.

> The lack of consideration in this regard in as far as budget allocations and progress in the upgrading of these facilities; together with other infrastructural projects in the pipeline, exacerbates the bed occupancy and the hospital stay of MDR- and XDR-TB patients in medical wards. This situation poses a threat of direct transmission of MDR- and XDR-TB to other patients who are otherwise admitted for other medical conditions ... In other situations, we are facing challenges wherein our TB patients end up lumped together with a result that those with ordinary TB are in danger of contracting MDR- and XDR-TB.\(^{236}\)
There is agreement that the prospect of a six-month incarceration in a drab hospital and the high death rates at these institutions is dissuading people with drug-resistant TB from presenting for a test or completing their treatment. Many delegates at the 38th Union World Conference on Lung Health agreed that most of the MDR-TB patients are not defaulters and will take their treatment if it is offered within their communities. Vuyiseka Dubula, a TB-HIV activist in Khayelitsha, suggests: “Centralised care is a death sentence. People will rather die at home undiagnosed than go to a place where they often don’t come back from.”

Indications are that the South African government is opposed to the decentralisation of MDR-TB treatment. Instead the Director General of Health, Thami Mseleku, has said that more hospital beds would be made available. Currently MDR-TB patients are facing waiting lists for beds.

One wonders why South Africa is not following the route of South American countries such as Brazil and Peru that have a decentralised, community-based approach to treating drug-resistant TB, rather than insisting on a method that is centralized and potentially high-tech, but also more expensive, more coercive, less patient-friendly, less safe for health workers and for hospital patients with HIV, less respectful of human rights – and that produces consistently less impressive results, world-wide. South Africa has a cure rate of just 58%, the third worst in the world after Uganda and Russia according to the WHO report, which suggests that many patients on treatment are defaulting.

Involuntary, indefinite isolation is presented by some health authorities as preferred official policy and the policy which perhaps not coincidentally dovetails with public anxieties about transmission and with public prejudice. However, if these official policies and practices were to be targeted for legal challenge on the basis that they infringed the rights of the patients affected without proper justification, they could be declared unconstitutional. Given that there are examples of other countries in which a similar TB epidemic has been effectively dealt with by measures that are respectful of human rights, a court would be hard pressed to accept that a coercive policy is justified.
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*Assented to*

![Signature]

*President of the Republic of South Africa*

During the last two months of 2007, Mr Justice Jon-Jo Douglas of Canada’s Ontario Court of Justice (Central East Region) heard the case of R. v. Wilde, in which the accused was charged with sexual assault allegedly committed against the complainant while he was in prison. In the course of the trial, while the complainant was giving evidence, it emerged that the complainant was HIV positive and that he also had hepatitis C. Soon after learning of the complainant’s illnesses, Judge Douglas ordered that he “be masked and/or testify electronically from another courtroom”. He said to the prosecution, “Either you mask your witness, and/or move us to another courtroom, or we do not proceed.” According to news reports, after the adjournment, “his court staff came out in blue rubber gloves and enclosed paper exhibits the witness had touched in sealed plastic bags.” Later in the trial Judge Douglas ordered that proceedings be moved to a larger courtroom so that there would be a greater distance between himself and the HIV-positive witness. When prosecution counsel assured him there was no need for such steps he insisted, “The HIV virus will live in a dried state for year after year after year and only needs moisture to reactivate itself.”

Even though the prosecution in this case challenged the treatment of the witness, going so far as to obtain expert medical evidence that HIV and hepatitis C were only transmitted through contact with certain body fluids, the judge rejected the evidence and said he would not continue the trial until he was satisfied that the “safety and integrity of this courtroom” was protected.

A number of organisations and individuals complained about Judge Douglas and his behaviour to the Ontario Judicial Council. One of these was the Ontario HIV and AIDS Legal Clinic, which is part of the Canadian HIV/AIDS Legal Network. The Toronto Star quoted an assistant professor at the McGill AIDS Clinic in Montreal as saying that the judge’s views were “outlandish” and that a drop of

“*The law knows no finer hour than when it cuts through formal concepts and transitory emotions to protect unpopular citizens against discrimination and persecution*”

– Justice Michael Kirby
human immunodeficiency virus drying on the floor would be inactivated within 20 minutes.

The Ontario HIV & AIDS Legal Clinic commented: “As lawyers working on HIV-related legal issues, we are deeply troubled by these reports of this sort of conduct by a judge (and other courtroom staff), which appear to depart significantly from the professional, ethical standards that are required. This is, we think, a particularly extreme example of unacceptable conduct by a judicial officer. Yet it seems unlikely that misinformation about HIV/AIDS, and hence the potential for bias and overtly prejudicial conduct, is limited to just this instance ... We urge the Ontario Judicial Council to conduct an appropriate investigation into these reports of this particular incident and to take appropriate steps to address the conduct of the judge in question, as well as considering a broader response to this manifestation of HIV-based stigmatisation and discrimination.”

The story of Judge Douglas and the non-intervention of the Superior Court of Justice is not necessarily the norm. Far more common are stories about members of the legal community who have taken the initiative to challenge, train or help their colleagues so that they are more prepared to deal with HIV and AIDS.

**ZAMBIAN JUDGES**

In September 2006, judges in Zambia\(^2\) celebrated the publication of their HIV/AIDS workplace policy document. This followed a research project which examined the effect of HIV/AIDS on the Zambian justice system.\(^3\) Judges drew it up the year following the release of a research project's findings which showed that extensive delays were being caused to trials because of HIV/AIDS. It also showed that chronic illness – assumed to be HIV/AIDS-related – was responsible for widespread problems in the court system, including 14% of cases ending in dismissals, and many court personnel were incapacitated or dying because of the epidemic.

In response to the report, which exposed the lack of a co-ordinated response to HIV/AIDS from the judicial system, the Zambian Chief Justice, Ernest Sakala, brought together members of his bench to work out a response. Their document was intended to serve as a “guideline to the judiciary on how to handle HIV and AIDS-related issues ... and promote proactive steps to enable those affected by HIV and AIDS to live healthy and productive lives”.
COURTS IN NEPAL

In Nepal the courts were proactive in ordering the government to pass legislation to protect people with HIV/AIDS. In December 2007, the Supreme Court in Kathmandu ordered that laws must be enacted to “ensure secrecy in the judicial process for cases involving people living with HIV/AIDS”. A news report added that the country’s apex court “also said it would formulate a set of guidelines for courts and the government outlining how such cases should be dealt with in court, until necessary new laws are enacted”. The order that the government introduce such legislation was made by Justices Khil Raj Regmi and Kalyan Shrestha, after the Forum for Women, Law and Development – a women’s rights NGO – brought public litigation to court on the issue.240

INDIAN LAWYERS

In the very month that Judge Douglas was ordering the HIV-positive witness before him to don a mask and stay a safe distance from the bench, Indian lawyers were responding to a request from the National Legal Services Authority for judges to mark World AIDS Day by educating themselves on the issue. Lawyer Asim Sarode conducted a session for judges and others in which he said that government legislation on the issue of HIV/AIDS and the courts was pending. “Even though there is no law now,” said Sarode, “the rights of the people with HIV/AIDS can be protected by the judiciary in the lower courts. And these steps can be taken even before the bill becomes the law.” This meeting was said to have been the first time that judges of the district court at Shivaji Nagar had been involved in a workshop to sensitise them on issues related to HIV/AIDS.

Included in the issues that judges needed to be aware of was the protection of people living with HIV/AIDS from discrimination at work, during marriage or divorce, and in prisons. In cases of divorce and dismissal of employees without specified grounds, the judge needs to enquire if HIV/AIDS is the reason, said Sarode. “There is also a precedent in the Bombay High Court law which allows anonymity to the parties – if they so wish,” he added.241

All these examples fit well with suggestions for action and education urged on the legal community by Australian Judge Michael Kirby. He says that HIV/AIDS is no longer “a remote, exotic, far-away problem for judges” and that they had to be alert to its legal dimensions.242 He proposes a programme of action for every lawyer and judge.
at the individual and collective level, which, if it were followed, would result in a judicial system far more aware of the legal and human rights of people living with the disease.

Kirby speaks of the fact that judges and lawyers invariably have an above-average education, enjoy a lifestyle privileged by comparison with many, and are respected because of the office they hold. This office, he says, imposes on them leadership responsibilities. This responsibility, individually and collectively, was particularly acute in relation to HIV/AIDS: “In the face of HIV/AIDS, lawyers everywhere must give a measure of leadership. The epidemic presents many problems of a legal character; but still more problems of prejudice, ignorance and discriminatory attitudes. This is why discrimination against people living with HIV/AIDS, or thought to be in that position, is sometimes described as the ‘second epidemic’”. 243

It isn’t good enough simply to understand and apply the law in relation to HIV/AIDS (though that is part of their responsibility). More is demanded since the epidemic is not about law as such, or statistics, but about human beings and fellow citizens. In the first instance he says that lawyers must be “conscious” of HIV/AIDS and the legal principles that affect lawyers in relation to the epidemic; they must know the facts about HIV/AIDS and all action and responses must then be based “upon sound data”. According to Judge Kirby every lawyer in every country, “should have more than a layman’s understanding of HIV/AIDS”. This is because it affects millions of people and “will have enormous implications for the running of courts, the decision-making in cases, relationships with colleagues and the legal profession’s role in the community”.244

The courts must approach the subject of HIV/AIDS with great sensitivity, he says. Prejudice and stigma is associated with the disease and it still has a significant association with death. “The association of HIV/AIDS with drugs, sex, and in particular, groups which have often been ... the subject of stigma (homosexuals, drug-addicted persons, sex workers, etc.) makes community responses to the epidemic highly sensitive and sometimes over-reactive”. 245 Lawyers ... cannot be entirely free from the attitudes, fears and prejudices of the societies they live in.” He urges judges and legal practitioners to be better informed, and to perform their functions as to reduce the burden upon people living with HIV/AIDS who come before them.

Discussing the duty of the court to help maintain the confidentiality of someone involved in a case, Judge Kirby surveys several landmark decisions, one of which, X v Y,
concerned two HIV-positive doctors. A newspaper had obtained their names from confidential records and wanted to publish, saying there was an important public interest in disclosing the information, as people were entitled to know the doctors’ serostatus. The court, however, did not agree to permit the publication of the names, saying people with HIV should not be deterred from seeking appropriate testing and treatment by the threat that their names could be disclosed. There is a further important point to be made about this decision. It stresses that “confidentiality in relation to a person’s HIV status could be important, not only to protect the interests of the infected person, but also for public health strategies generally, against the spread of the epidemic”. In other words this decision illustrates yet again that a concern for, and protection of, human rights (in this case the right to confidentiality) feeds into a public health strategy and supports it, rather than being inimical.

The issue of confidentiality also emerged in a case from the Bombay High Court mentioned by Judge Kirby. It involved a casual labourer who was marked for promotion, but in the course of the tests required before the promotion could take effect he was found to be HIV positive. The point made by Judge Kirby about the court’s handling of the case was its “considerable sensitivity” in ordering that the names of those involved should not be published. “Some people, denied confidentiality,” he remarks, “would simply abandon their rights at law or never come to court.” This is something that legal representatives must be aware of in relation to their clients.

Judge Kirkby stresses that there will often be a need for urgency in cases where some of those involved have AIDS. “Unless lawyers become pro-active and take control of litigation involving people suffering from HIV/AIDS, the litigant may be improperly denied a right or remedy, and such loss may prove irreparable”. This is a problem already well known in South Africa, where a number of cases before the courts involving people with AIDS have been resolved only after the person has died.

One of the most challenging aspects of Judge Kirby’s remarks is his insistence that every judge and legal practitioner must intervene to prevent irrational discrimination on any grounds including the sero-status of the person targeted. In other words, no officer of a court should sit in silence if someone, in argument or in evidence, uses language that is derogatory and discriminates against anyone else. This includes discriminatory language in connection with someone’s HIV status. This would extend as well to the other issues discussed in this Review – children, migrants, prisoners, people with TB and the vexed questions of testing and circumcision.
Among the areas where a judge will have to make difficult decisions related to HIV/AIDS are matters of sentencing people known to be infected, or ordering the release of prisoners who are very ill with the disease; by staying up to date with other rulings on such issues a judge will be more easily able to weigh up the competing interests involved.

Presiding officers will also often need sensitivity on HIV/AIDS to make decisions concerning family law, refugee status and employment cases relating to discrimination, among others. “In such cases especially, judges need to ground all decisions upon sound data resting on the evidence – not on prejudice, stereotypes, myths or pre-judgment.” Judicial rulings must be informed with accurate knowledge about HIV/AIDS, “so that prejudice is replaced by knowledge; and stereotyping by judicial commitment to equal justice under the law.”

Legal practitioners should not be concerned only about their clients who are HIV positive, however. They should also extend that concern to colleagues who are affected. “They should ensure that they are received without discrimination, but with support, where that is appropriate, and accommodation where it is necessary.” And among those to whom support and comradeship should be extended are not just other judges but also court staff, police and their families.

NEW JERSEY COURT POLICY

One jurisdiction that seems to be practicing much of what Judge Kirby suggests is that of New Jersey in the United States. There, a policy on HIV/AIDS has been drawn up for the courts, based on principles developed by the New York, New Jersey Citizens Commission on AIDS and adopted by the National Leadership Coalition on AIDS (available at www.csa.za.org under ‘Downloads’). The document was drawn up for two main purposes, namely to “reinforce the commitment of the judiciary to serve everyone who uses the courts, including those with disabilities, such as HIV/AIDS”, and to help ensure that the court continues to “provide a safe, healthy, non-discriminatory environment for its employees and users”.

As far as its own employees are concerned, the judiciary elaborates on what it means by saying it has a policy of non-discrimination in relation to employment. It begins by listing legislation that prohibits discrimination in employment “based on a physical or mental disability or the perception of such a disability”. It continues, “People living with
HIV have a protected disability under [these laws]. Workplace policies and procedures addressing employees with HIV must be consistent with those addressing all other employees with disabilities ... This includes but is not limited to the hiring, firing, and refusal to promote on the basis of an actual or perceived disability, including infection with HIV."

Anyone working for the judiciary (or for any other employer) should expect to work in an environment free of harassment or prejudicial treatment by colleagues. The New Jersey policy document makes provision for ensuring that this is the case. “Harassment or discriminatory treatment of people with or perceived to be infected with HIV is expressly prohibited by the judiciary. Managers and supervisors who discover that workplace harassment or discriminatory treatment is occurring have a responsibility to eliminate it. Non-supervisory staff are encouraged to report instances of harassment or discrimination to their designated affirmative action representative.”

The New Jersey document suggests that there may be occasions when it would be appropriate for the results of such tests to be disclosed, but the judiciary is urged to be sensitive to the issues and “avoid placing unnecessary HIV information in public court files”. For example, if an adjournment request were based upon some HIV-related health condition of an attorney, witness or party, consideration should be given to either sealing the medical information or not including it within the public court file.

It is possible that someone who is HIV positive has a special need requiring a particular form of “reasonable accommodation” or that someone “may genuinely present a public health challenge”. When that happens, and “[w]here special facts or circumstances give rise to medical or public health issues, such cases will be individually evaluated using appropriate factual and scientific evidence.” The judge assigned to a case will make any decisions in relation to problems that occur during that case; when the issue arises in an “administrative setting”, a specially designed judge will take responsibility for decisions.

One of the most impressive sections of the policy document is the commitment to ongoing training of judiciary personnel, with the allocation of a staffer whose task is to ensure that information is up to date and available.

The policy document is also very clear about confidentiality, stressing that the judiciary has a legal obligation to protect the confidentiality of all employees’ medical records, including those related to their HIV status.
A policy document like this is an excellent means for the courts to ensure that they participate in public education about HIV/AIDS. Such a document shows the court’s commitment to treat both its own staff and members of the public, living with HIV, in a way that respects their human rights, their dignity, their need for confidentiality, their need to work, and their special needs, if any.

WHAT ABOUT SOUTH AFRICAN COURTS?

There is no jurisdiction in South Africa with a policy document on HIV and AIDS. However, it may be useful for the judiciary to begin as soon as possible to develop such a policy. If this were to happen, the South African judiciary would not be the first on the continent to produce a policy commitment on HIV and AIDS. However, such a step would align well with the values of our Constitution.

Training of presiding officers on issues surrounding HIV/AIDS is not yet a requirement in South Africa, although if a policy document similar to the New Jersey policy were to be formulated, it could specify that this was necessary. However, some groups have been trained on the subject. Among them are a number of magistrates who were offered training by the Centre for the Study of AIDS at the University of Pretoria in late 2007. The group reflected at the end of their workshop that they realised HIV and AIDS had implications for the running of courts in South Africa and that judicial officers had a duty to be aware of the essential facts about the illness (rather than perpetuating erroneous myths), as well as knowing and understanding relevant legal principles which would affect them in the performance of their professional tasks.

As far as the operation of the courts was concerned, the magistrates said a number of changes could be made to ensure that people with HIV and AIDS found the courts easier to negotiate and less hostile. Among their suggestions were to:

- create a sensitive and empathetic environment, even among court personnel
- designate certain rooms as waiting rooms for the public and witnesses: use these rooms as places where videos on various social issues – particularly stigma and discrimination – could be aired
- provide material on HIV and AIDS (as well as condoms perhaps), at information desks and other appropriate places in court buildings
- ensure that lifts at courts worked and that there were ramps for wheelchairs, as well as a wheelchair available for use in each court should it be needed
- ensure that there were basic first aid facilities at the court and if possible occupational safety officers and social workers, and...
• provide the basics: a hygienic, clean and friendly atmosphere in and around the court.

The group recognised that HIV was increasingly prominent as an issue in South African case law. HIV/AIDS-related cases that came to court included criminal law (bail and sentencing matters as well as the question of intentional exposure to HIV), family law, immigration, adoption, employment, insurance and other cases in which discrimination played a role. It was important, group members said, for judicial officers to have sound basic knowledge about HIV and HIV case law so that they would not be caught unawares when such issues arose in court.

The magistrates participating in the workshop found that they were likely to have to consider HIV/AIDS issues in connection with civil, criminal and family law matters, and they listed some issues likely to involve HIV/AIDS that could occur under each branch of the law. Civil law cases included defamation, breach of privacy, *injuria*, discrimination in equality courts and debt collection. Criminal law cases included bail applications, sentencing, and trials for assault, murder, *crimen injuria*, rape and other sexual offences. Family law cases included domestic violence protection orders, foster care and adoptions, and maintenance.

The group was also concerned about the need to protect confidentiality in HIV-related cases. They agreed that a balance had to be struck between the public’s right to know and a litigant’s right to privacy, and that because there was no clear-cut formula about which should be given greater weight, each case should be decided based on the particular facts.

Following the analysis of Judge Kirby, the magistrates acknowledged that they should be aware of colleagues living with HIV/AIDS. They also agreed that judicial officers were part of the broader community and as such they needed to consider what role they could play in responding to the epidemic as it manifested itself beyond the courts.

In the years since 1994, and since the adoption of the Constitution, awareness has grown in South Africa about the role of the Constitution and its central position in law making and interpretation, and the protection of human rights. Organisations exist in South Africa to help people who need access to the law in order to challenge infringements of their human rights. Some of these focus on HIV/AIDS and have been able to test discriminatory practices in business, government and other spheres. They have been helped by an apex court that is deeply committed to its task as guardian of the concepts of dignity and respect.
However, despite the protections offered by the Constitution, the majority of South Africans are still unable to access these protections directly, through legal action, because of ignorance, poverty and sometimes because of fear. People who need help in relation to HIV/AIDS are among those who cannot find a way to solve their particular legal problems or to prevent their human rights from being violated through discrimination, prejudice, ignorance or arrogance.

Although many members of the legal community have been trained under the new dispensation, most have not been given specific training on questions relating to HIV/AIDS. This includes most presiding officers in the upper and lower courts.

Two possibilities appear promising. The first is for training within the legal community on HIV/AIDS to continue, but in a more systematic way. Training should involve a wide range of related issues, including the impact on the human rights of those living with HIV and AIDS, and how the courts and the legal profession can respond. The second is to follow the example of the New Jersey judiciary and their colleagues in Zambia and to formulate a policy document on HIV and AIDS. Many members of the judiciary could be involved in drawing up such a document and thus sensitised to the issues involved.

But it is not just the judiciary and the legal profession who need to be trained in this way – this Review has discussed some of the areas where public health decisions have a direct impact on human rights – often this impact is negative. Human rights can also be used to challenge such public health provisions and responses and ensure that laws and policies are adapted and changed. It is in the interests of both groups that the tensions between public health and human rights are eased. For this to happen, public health needs to pay far greater attention to the social and lived realities of the people for whom they are designing policies and interventions. People’s understanding of themselves, the possibilities in their lives and of illness and death and are informed by the social environment in which they live. Public health interventions that see people as universally the same, able to make choices and act on their lives are likely to have limited impact. Likewise, the power of social influences need to be recognised as often being far stronger than the rational messages of public health. Similarly human rights need to engage with how communities can utilise legal capital to ensure that public health serves both personal and social health needs and protects the rights and dignity of all.

Obviously, the right to health and the ways to exercise rights depends upon health and legal workers, who enhance
public health, deliver medical care and are vigilant about human rights. The classic traditional objectives of the health and legal professions can benefit from the new, dynamic discipline of human rights. Health workers and the legal profession can use the right to health to help them devise equitable polices and programmes that benefit the most disadvantaged and excluded; strengthen health and legal systems; place important health and rights issues higher up national agendas; secure better coordination across health and related sectors; leverage more money from treasury and improve the terms and conditions of those working in both sectors.

Finally in the words of Paul Hunt, special rapporteur on the right to the highest attainable standard of health: 

*In short the right to the highest attainable standard of health is an asset and ally, which is at the disposal of all health workers.*

The same applies to human rights.
2 This is a crude oversimplification, but the phrase ‘public health versus human rights’ is often used.
6 Ibid.
7 Ibid.
11 Ibid.
16 It should not have been possible for the levels of discrimination around HIV to have developed over what is essentially another physical characteristic like race or gender.
17 Baldwin Ibid.
19 Baldwin Ibid.
20 This is not to suggest that it is an issue of either individual rights or public health, but rather to question the ways in which public health has been able through its history and social position to violate human rights and defend this position.
21 Doka p 7.
22 Beardslee
23 Beardslee
26 Doka p 10.
27 Ibid.
28 Doka p 18.
31 Doka p 28.
33 Ibid.
36 Dokra p 56.
Dokra p 80.


Dokra p 80.

Ibid.

Dokra pp 138-139.


The term genealogy here refers to the uncovering of the rise of discourses, power relations, and bodies of knowledge over time in order to construct a ‘history of the present.’

See for example: M. Foucault (1975) The birth of the clinic.


Musto D cited in Bayer R (2008) Stigma and the ethics of public health: not can we but should we. In Social Science and Medicine 67.


Lupton op cit.

Ibid – text adapted.


The most compelling cases in this regard are the rise in domestic violence with the introduction of the routine offer of an HIV test and the refusal of men who have been circumcised to use condoms – both have serious social (and indeed medical) implications, but the public health discourse seems unwilling to engage with these issues.


Ibid.

Gruskin S & Tarantola D Health and human rights.

See Marks SP Health from a human rights perspective p 15.

Ibid.


Ogilvie, in Fee & Fox, p 144.


Ibid.


Gostin L & Mann J (1999) Toward the development of a human

70 Ibid.
71 Ibid.

74 Ibid.
75 Ibid.


80 Ibid.
81 Ibid.

83 Ibid.


87 Ibid.


90 Ibid.


94 On this issue the work of I Niehaus is particularly illuminating – his field work done in Mpumalanga offers different understandings of sex and sexual violence.

95 Take note, for example, of the defence in the Jacob Zuma rape trial that the dress of the complainant required the sexual act, as well as the sexual humiliation of a young woman at a Johannesburg taxi rank where she was stripped and assaulted because the male taxi drivers took exception to her clothing.


104 *Ibid*.

105 ALP p 3.

106 *Ibid*.

107 ALP p 6.

108 ALP p 6.


110 ALP p 5.


112 Richardson op cit p 49.

113 See for example, the reports of taxi drivers stripping and abusing a young woman at a taxi rank because she was ‘inappropriately dressed’ and the section of the defence of Jacob Zuma in his rape trial where it was stated that in his culture, forms of dress led to an expectation of sexual relations.

114 *Scared at school* op cit p 27.

115 ALP p 8.


118 *Ibid*.


120 National Working Group pp 4-5.


123 ALP p 4.

124 ALP p 7.


129 ALP p 13.

130 No minimum age restriction was prescribed in the relevant law on corporal punishment, but it was generally imposed only on children of nine years and older.

Male circumcision is not the HIV “vaccine” we have been waiting for. Available at: www.futuremedicine.com/doi/full/10.2217/17469600.2.3.193


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See, for example, Committee on Economic, Social and Cultural Rights (2000) The right to the highest attainable standard of health: CESC general comment 14, UN Doc. E/C.12/2000/4, par 8 “The right to health contains both freedoms and entitlements. The freedoms include the right to control one’s health and body, including ... the right to be free from interference, such as the right to be free from ... non-consensual medical treatment and experimentation.”

Universal Declaration of Human Rights arts 1 and 3.

See for example, articles 1 and 3 of the Universal Declaration of Human Rights and articles 9 and 10 of the International Covenant on Civil and Political Rights (ICCPR).
163 See, for example, article 29 of the Universal Declaration, the Siracusa Principles on the Limitation and Derogation Provisions in the ICCPR, as well as section 1 of the Canadian and section 36 of the South African Constitutions.


166 Masa information booklet, note 3, at 7.

167 Masa information booklet, note3, at 1.

168 Bozzette (note 9 above) concedes that distrust and fear of “routine screening” may “lead some patients to avoid needed care for other conditions” (at 621).


173 The MRC report on orphans claimed that “it is encouraging that the communities likely to be worst hit by the orphan burden tend to regard orphaned children as the responsibility of the community rather than the responsibility of the government.”


177 The keeping mothers alive belief in no way implies that it is not also important to keep fathers alive – but most young children live with their mothers (or grandmothers).


180 See the International Convention on the Rights of the Child (ICRC).


182 Ibid.

183 Ibid.

184 Ibid.

185 Ibid.

186 See www.unicef.org/crc/bg005.htm


188 Ibid.


190 Poku op cit 95.


193 Ibid, p 304.


200 Ibid.

201 Ibid p 295.


203 Jonathan Berger interview.

204 Ibid.


206 The United Nations Universal Declaration of Human Rights is regarded as the mainspring of all human rights existing today and it clearly provides that prisoners, like everyone else have a right to medical care and other necessary social services.

“Article 25 of the Declaration provides everyone, including prisoners, with a right to a standard of living adequate for personal health and well-being, including food, clothing, housing, medical care, and other necessary social services. This Declaration also protects prisoners in terms of Article 5, from being tortured.

“Th(is) Declaration led to the formation of other international instruments (International Covenant on Civil and Political Rights, the Covenant on Economic, Social and Cultural Rights and several other regional human rights conventions) protecting human rights, including prisoners’ rights to health care services.

“The Convention against Torture and Other Cruel, Inhuman or Degrading Treatment (1987), in terms of article 2 (1) protects prisoners’ rights to health care services by imposing an obligation on states to take effective legislative, administrative, judicial or other measures to prevent acts of torture in any territory under their jurisdictions. The International Covenant on Economic, Social and Cultural Rights (1976) recognises, in terms of article 12, the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. Article 7 of the International Covenant on Civil and Political Rights (1966) provides that no-one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment, and no one shall be subjected without his free consent to medical or scientific experimentation. This Covenant, in terms of Article 10, imposes a positive duty on the parties to ensure that prisoners are treated with respect and human dignity. (Human dignity), it ought to be stressed, also embraces the provision of good health care services in prisons.

“International human rights instruments providing for prisoners’ rights to health care services include, The Standard Minimum Rules for the Treatment of Prisoners (1955), The
Basic Principles for the Treatment of Prisoners (1990), Body of Principles for the Protection of All Persons under Any Form of Detention or Imprisonment (1988) and The United Nations Rules for the Protection of Juveniles Deprived of their Liberty (1990). These international instruments in essence provide that prisoners should be respected and treated with human dignity. At a regional level, protection of prisoners’ rights to health care services include the European Convention for the Protection of Human Rights and Fundamental Freedoms, the American Convention on Human Rights, and the African Charter on Human and People Rights. In terms of Article 3 of the European Convention, no one shall be subjected to torture or to inhuman or degrading treatment or punishment. With regard to this right there is no distinction between the status of a prisoner and that of a free person. In terms of Article 5 (2) of the American Convention on Human Rights, no one shall be subjected to torture or to cruel, inhuman, or degrading punishment or treatment. The same argument that was made in respect of Article 3 of the European Convention can also be made in the analysis of Article 5 of the American Convention, namely that the right in terms of Article 5 does not distinguish between a prisoner and a free person. Therefore all persons including prisoners are entitled to this right. The same analysis can also be submitted in respect of Article 5 of the African Charter on Human and People’s Rights. Article 5 prohibits all forms of exploitation, particularly slavery, slave trade, torture, cruel, inhuman or degrading treatment.”

207 The Times 13 May 2008.
208 Ibid.
210 Ibid.
211 Ibid.
212 The organisations involved in the submission were the AIDS Law Project (ALP), Legal Resources Centre (LRC), Lawyers for Human Rights (LHR), Treatment Action Campaign (TAC), Consortium for Refugees and Migrants in South Africa (CoRMSA), Médecins Sans Frontières (MSF) SA, Forced Migration Studies Programme (WITS), People Against Suffering, Suppression, Oppression and Poverty (PASSOP), AIDS and Rights Alliance of Southern Africa (ARASA), Centre for Applied Legal Studies (CALS), Wits Law Clinic, Southern African HIV/AIDS Clinicians’ Society (SAHCS), South African Council of Churches (SACC), AIDS Consortium, Bowman Gilfillan Attorneys Pro Bono Department and Webber Wentzel Bowens Attorneys Pro Bono Department.


214 Ibid.
215 Ibid.
216 Ibid p 8.
217 Ibid.
218 Ibid p 9.
219 The AIDS Law Project and the Treatment Action Campaign are supported in their concern by a number of other organisations that endorse the submission. They are the AIDS and Rights Alliance of Southern Africa, the AIDS Consortium, the Children’s Rights Centre, the Consortium for Refugees and
Migrants in South Africa and the Forced Migration Studies Programme, Lawyers for Human Rights, the Legal Resources Centre, People Against Suffering, Suppression, Oppression and Poverty, the Public Interest Law Unit at Webber Wentzel Bowes Attorneys, the Rural Doctors Association of South Africa, the Southern Africans HIV/AIDS Clinicians’ Society, the South African Council of Churches, the Wits Law Clinic and Young Women Across Borders.

220 Joint ALP/ TAC Submission on the Refugees Amendment Bill [B 11-2008], presented with an oral submission, to the Portfolio Committee on Home Affairs, 26 March 2008, p 3.

221 Ibid.

222 Ibid.


224 They come to us for sanctuary, but walk into a nightmare, Majodina Z, Cape Argus, 30 June 2006. Available at: http://www.capeargus.co.za/index.php?fSectionId=137&fArticleId=3318039


226 See www.worldcarecouncil.org/

227 Available at www.worldcarecouncil.org/


231 Plan p 15.

232 Ibid.
The Centre for the Study of AIDS (CSA) is located at the University of Pretoria. It is a ‘stand alone’ centre which is responsible for the development and co-ordination of a comprehensive University-wide response to AIDS. The Centre operates in collaboration with the Deans of all Faculties and through Interfaculty committees to ensure that a professional understanding of the epidemic is developed through curriculum innovation as well as through extensive research.

Support for students and staff is provided through peer-based education and counselling, through support groups and through training in HIV/AIDS in the workplace. The CSA in partnership with the Campus Clinic and staff at Pretoria Academic Hospital offers a full ARV rollout with counselling, testing and treatment. A large number of student volunteers are involved in the various CSA programmes, as are many community groups, ASOs and NGOs.

To create a climate of debate and critique, the CSA publishes widely and hosts AIDS forums and seminars. It has created web and email-based debate and discussion forums and seeks to find new, innovative, creative and effective ways to address HIV/AIDS in South African society.

Together with the Centre for Human Rights and the Law Faculty at the University of Pretoria, the Centre has created the AIDS and Human Rights Research Unit. This research unit is continuing the research into the relationship between AIDS and human rights in the SADC countries, is engaged in the development of model legislation, of research in AIDS and sexualities and sexual rights, and in the placing of interns to work in various sub-Saharan parliaments and with parliamentarians to strengthen the role of parliaments and governance. The AHHRU recently published a book on aspects of its research – *Human Rights Under Threat*, edited by Frans Viljoen and Susan Precious.

between AIDS and human rights in eight of the SADC countries and how the ways in which a rights-based or a policy-based approach has determined the ways in which people living with HIV or AIDS have been treated and the rights of populations affected.


The CSA operates in consultation with an advisory reference group – TARG – comprised of university staff and students from faculties and service groups as well as community representation. The CSA has developed a close partnership with a number of Southern and East African Universities through the Future Leaders @ Work Beyond Borders initiative as well as the programme to develop university-based responses as well as the programme to develop university-based responses that address the needs of students and staff living with HIV and AIDS.

The CSA continues with its core work and amongst other partners works closely with the SADC PF based in Windhoek on model legislation and issues of criminalisation, and has interns placed in other African parliaments and universities. Through an extensive community based programme in Hammanskraal paralegal and community based health and human rights workers are trained and supported. The CSA has two stigma projects currently in Hammanskraal through which they are working with magistrates, the police and other agencies on issues of HIV and AIDS-related stigma.

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Human dignity is identified as the bedrock of freedom, and is of prime importance to the study of food insecurity.
Human dignity is identified as the bedrock of freedom, and is of prime importance to the study of food insecurity.

"The 'Red death' had long devastated the country. No pestilence had ever been so fatal, or so hideous … The scarlet stains upon the body and especially upon the face of the victim, were the pest ban which shut him out from aid and from the sympathy of his fellow men. But the Prince Prospero was happy … when his dominions were half populated, he summoned … a thousand … friends among his knights and dames to his court, and with these retired to the deep seclusion of one of his castellated abbeys. The abbey was amply provisioned. With such pre-cautions the courtiers might bid defiance to contagion. The external world could take care of itself." – Edgar Allan Poe, The Masque of the Red Death, 1842

"… my dear friends turned their backs on me as if some pursuing enemy had his sword at their throats, without giving a single thought to the obligations of human fellowship and friendship." – Joseph Grünpeck, Libellus Josephi Grunpeckii de mentalagra, alias morbo gallico, 1503 cited in C Quetel (1990) History of syphilis p17.

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