

5th SA AIDS Conference, ICC Durban – Keynote Address

**THE PROBLEM IS US:
THE ROLE OF PUBLIC POLICY AND LAW IN THE FIGHT
AGAINST HIV AND AIDS**

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Keynote Address

Chief Justice Sandile Ngcobo

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INTRODUCTION

Ladies and gentlemen – I am honoured to be with you at the opening of the 5th SA AIDS Conference. Thank you to Prof Venter for this invitation and for your warm introductory remarks. It is a privilege to be here.

In considering the theme for this year's conference – “Leadership, Delivery and Accountability” – I have asked myself how the diverse set of actors gathered, here, which includes scientists, policymakers, public health advocates, and donor organisations, amongst others, can work together in the fight against HIV and AIDS.

We have made significant progress in HIV and AIDS science. That is why the tone of this conference, rightly, is different from many that have gone before. Treatment is now accessed by nearly 1.5 million South Africans. Government is taking positive steps to improve prevention efforts. The mass testing campaign has, itself, given over 10 million South Africans knowledge of their own HIV status, and, in doing so, helped reduce ignorance, fear and stigma.

These are massive gains, and they are worth celebrating.

But not everything that can and should be done is being done. The result is that these benefits still do not reach everyone who needs them. The question I believe we should ask ourselves is why is this so?

The answer is that the problem is no longer the virus. The problem is us. I say this because, in the fight against HIV and AIDS, the tremendous advances in scientific knowledge over the past decade must be matched by parallel advances in public health policy and law in order for advances in the laboratory to translate into better outcomes for affected communities.

We must, of course, celebrate the advancements made in science in dealing with the epidemic. But being mindful of my limited time with you this afternoon, I would like to reflect on the critical role that policy and law can and should play in the fight against HIV and AIDS.

SCIENCE

It may be useful to briefly recap the tremendous progress made in a relatively short time in HIV medical science.¹

Almost as rapidly as the virus exploded onto the global scene it was attacked in laboratories. I am hardly qualified, particularly in a group as sophisticated on the matter as this, to set down all the turning-points in the battle against HIV and AIDS. But I would like to note that it took scientists only 15 years to get from what was

¹ For a timeline of the outbreak and scientific advancements in the fight against HIV and AIDS, see <http://www.avert.org/aids-timeline.htm>; also see www.apositivelife.com/forasos/hiv-aids-milestones.html.

thought to be a mysterious gay disease in 1982, when the “AIDS” acronym was coined in the United States, to the first generation of Highly Active Anti-Retroviral Therapy, or “HAART”, in 1997. In 2006, circumcision was shown to reduce HIV infection among heterosexual men. In 2010, the ARV-based vaginal gel CAPRISA 004 was found to dramatically reduce the risk of HIV infection in trials led by the Centre for the AIDS Program of Research in South Africa.² And most recently, in May 2011, results of the HPTN 052 study showed that an HIV-positive person is 96% less likely to transmit the virus to a HIV-negative partner if the positive individual begins ARV treatment immediately upon diagnosis, as opposed to at a later stage as per current international guidelines.³

Despite these advances, the life-saving drugs that people in many parts of the world have been able to access since the 1990s are still a scarcity where they are needed most. Protection from transmission, access to treatment, care and support, and freedom from stigma, exclusion, discrimination and violence for those who are infected or affected are still only a distant dream for many today. It is for this reason that, I put to you, the problem is no longer the virus. The problem is us.

² See <http://www.ipmglobal.org/publications-media/new-science-new-hope-milestone-hiv-prevention-proof-concept-established-arv-micr-0>.

³ See <http://www.aidsmap.com/page/1796327>.

PUBLIC POLICY

In fairness to the policymakers and advocates in the room, let me first say that there have been great strides made in the prevention and treatment of HIV and AIDS over the last decade. According to the 2010 UNAIDS Report, the number of new infections has fallen by nearly 20%, globally, over the last decade. In sub-Saharan Africa, the epidemic has either “stabilised or [is] showing signs of decline”.⁴

I am very proud that, here in South Africa, we have reportedly achieved 95% coverage of treatment to prevent mother-to-child HIV transmission.⁵ Since April 2010, there have also been policy revisions that are expected to expand access to treatment for pregnant women and infants, including universal coverage of women with CD4 counts below 350, as opposed to 200, and starting PMTCT at 14 rather than 28 weeks of pregnancy.⁶ We are also aware that the government’s goal is to completely eliminate mother-to-child transmission of HIV.⁷

⁴ *UNAIDS Report on the Global AIDS Epidemic* (2010) (UNAIDS Report), available at http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2010/20101123_globalreport_en.pdf, at 8 and 34.

⁵ *Id.* at 10; see also *South Africa’s UNGASS Report for the period January 2008 - December 2009* (2010 UNGASS Report) at 35: “Prevention of Mother-To-Child Transmission of HIV (PMTCT) is now almost universally available in public primary health facilities, and South Africa achieved the NSP target of >95% coverage in public sector antenatal service sites in 2008”.

⁶ *The Health Budget Vote Policy speech by Minister of Health Dr A Motsoaledi* National Assembly (31 May 2011) (Minister for Health Budget Speech) confirms these measures taken since April 2010:

“These measures, of starting ARVs when the CD4 count is 350 or less in pregnant women and HIV/TB co-infected people, of starting PMTCT at 14 rather than 28 weeks and of treating HIV positive newborns regardless of CD4 count has gone a long way in reversing the tide of HIV and AIDS.”

⁷ *Id.*

That is all very good news indeed, for which we must acknowledge and thank all those who were involved in bringing about such milestones. There is, however, as you know, also bad news. Sub-Saharan Africa still bears an inordinate share of the global HIV burden. In sub-Saharan Africa, there are nearly one third more people living with HIV now than a decade ago.⁸ According to UNAIDS, at the end of 2009, of the estimated 33 million people globally living with HIV, nearly 68% were in sub-Saharan Africa⁹; and of the nearly 2 million deaths attributable to HIV-related illnesses, 72% were in sub-Saharan Africa.¹⁰ Even in what appears to be the golden age of HIV science, sub-Saharan Africa still experiences a yearly HIV and AIDS catastrophe.

In South Africa, the estimated number of people living with HIV rose more than 20% between 2001 and 2009, to nearly 6 million people¹¹. The vast majority of new infections were women.¹² Women aged 20–34 have the highest HIV prevalence in the country, with approximately one out of three women affected.¹³ Children and adolescents losing one or both parents due to AIDS more than tripled, with the numbers ranging from 1.3 to 3 million children.¹⁴ We are also listed among countries

⁸ UNAIDS Report at 28.

⁹ Id at 21-2.

¹⁰ Id at 25.

¹¹ See id at 180. The estimated number of people in South Africa living with HIV rose from 4.6 to 5.6 million between 2001 and 2009.

¹² During the period of 2001 to 2009, the number of South African women living with HIV rose from 2.6 to 3.3 million. Id at 182.

¹³ See 2010 UNGASS Report at 24.

¹⁴ UNAIDS Report at 186; see also 2010 UNGASS Report at 46.

with coverage of less than 40% of adults living with HIV receiving anti-retroviral therapy.¹⁵

Statistics can't tell us everything about the problem we are trying to solve. But statistics such as these should give us a sense that something is not right. They seem dissonant with what we know of the medical advances made in HIV and AIDS prevention and treatment. Given these advances, why are mortality and infection rates still so high? Why are there still so many who do not or cannot access treatment, care and support? These are the kinds of questions such statistics raise for me.

I surmise that the problem, in part, has to do with policy and its implementation – in areas of policy that governments, as well as other stakeholders, may at times be uncomfortable, unwilling, unable or simply too slow to act on. The issues surrounding infection and treatment that we face in relation to gender inequality and gender-based violence, intravenous drug use, and the sex trade are examples of such policy areas. The recent decision by the Board of the Global Fund to Fight AIDS, Tuberculosis and Malaria to include ministers in charge of labour and mining, as well as labour unions, in discussions around coordinated efforts to combat both AIDS and non-communicable diseases is both encouraging and revelatory of the complexity in formulating policy around these issues.

¹⁵ UNAIDS Report at 97.

I am not a policymaker, and I am thankful for that. It cannot be an easy responsibility to shoulder. I will not, therefore, attempt to debate public health policy. I know you will have time between now and Friday to engage in such debates.

What I want to leave you with is the question of how we can think critically and innovatively about our policies to ensure that they are up to speed with science, which has come so far. In my own view, any coordinated effort to fight the global epidemic is one that will only succeed if it is nimble enough to re-focus and change strategies as the terms of the battle shift. We must ask ourselves if we have successfully made the transition to a fight that is as vigorously focused on progressive, informed policy and its implementation as it is focused on medical advancements.

I must be clear that I do not mean to suggest that no progress has been made in HIV and AIDS policy. The South African National AIDS Council (or SANAC), is, I believe, in the process of developing its next, and third, five-year HIV and AIDS national plan to be released later this year.¹⁶ However, as SANAC recognised in its 2007-2011 plan, a “supportive legal and policy framework is critical for effective implementation of key aspects of the plan.”¹⁷

¹⁶ SANAC’s 2007-2011 Plan (NSP) aimed to reduce the number of new infections, especially among young people, and reduce the impact of HIV and AIDS on individuals, families, communities and society. It focused on four priority areas: prevention; treatment, care and support; human and legal rights; and monitoring, research and surveillance.

¹⁷ 2007-2011 NSP at 145.

This brings me to the question of how law intervenes in the fight against HIV and AIDS.

LAW

To understand the role that law can play in the fight against HIV and AIDS, it is necessary to recall what the history of HIV and AIDS has been about. It has been a struggle for the normalisation of the disease; a struggle to have it treated as any other disease. It has also been a struggle against stigma; a struggle for equality and justice; a struggle against discrimination against people living with HIV and AIDS; and a struggle for access to treatment for those dying of AIDS. Perhaps, most importantly, it has been a struggle for rationality against irrationality in the public response to the disease.¹⁸

Stigma was at the heart of this struggle. AIDS has probably been one of the most, if not the most, stigmatised disease in human history. Those who have it are blamed for their own condition and are morally condemned for having it. This has likely been because AIDS is frequently a sexually transmitted disease and because it is prevalent among poor and socially marginalised groups.

¹⁸ This list draws from an eloquent exposition on the history of the epidemic, viewed in terms of struggle, by my colleague, Edwin Cameron. See Edwin Cameron, “Legal and Human Rights Responses to the HIV/AIDS Epidemic”, Special Lecture at University of Stellenbosch, Faculty of Law (12 October 2005) at para 9, available at http://law.sun.ac.za/portal/page/portal/law/index.english/news/2005/judgecameron_lecture.pdf.

Stigma manifested itself in prejudice and discrimination against people living with HIV and AIDS. Prejudice and discrimination, in turn, had a devastating effect on those suffering from the virus. They prevented HIV-positive people from revealing their HIV status for fear of prejudice. This denied them, and often their families, access to critical treatment and care. The consequences for the country have been catastrophic. Millions of people died and many millions more became infected.

Both international human rights law and South African law have meaningfully intervened in response to discrimination and prejudice on the basis of HIV status.

In 1995, the United Nations Commission on Human Rights took a definitive stand against HIV and AIDS-related discrimination, calling for HIV status to be recognised as a protected status under international human rights law.¹⁹ This was reiterated by the Commission in 2005, when it called upon states, in the light of advancements in treatment technology, to enable access to HIV treatment, placing emphasis on “the urgent HIV-related human rights of women, children and vulnerable groups.”²⁰

In 2009, the Committee on Economic, Social and Cultural Rights similarly emphasised that HIV status qualified as a health status with respect to which

¹⁹ The full text of UN Resolution 1995/44 is available at <http://www.unhchr.ch/Huridocda/Huridoca.nsf/TestFrame/fc3166481a80a19b802566db00528845?Opendocument>.

²⁰ The full text of UN Resolution 2005/84 is available at <http://www.unhcr.org/refworld/category,LEGAL,UNCHR,,,45377c970,0.html>.

discrimination was impermissible under the International Covenant on Economic, Social and Cultural Rights.²¹

In South Africa, courts have played a critical role in dismantling structural discrimination against those with HIV and AIDS.

In the case of *Hoffmann v South African Airways*,²² the Constitutional Court was called upon to consider workplace discrimination against people living with HIV. The Constitutional Court found SAA's policy of refusing to employ HIV-positive cabinet attendants to be unfair discrimination, and to violate the constitutional rights to equality, human dignity and fair labour practices. The Court also found that SAA's defence of its discriminatory employment practices, which it attempted to justify on safety grounds, was inconsistent with the medical evidence presented to the Court.

In *Hoffmann*, the Court described discrimination against HIV-positive persons as follows:

People who are living with HIV . . . have been subjected to systemic disadvantage and discrimination. They have been stigmatised and marginalized . . . Society's response to them has forced many of them not to reveal their HIV status for fear of prejudice. This in turn has

²¹ The full text of CESCR General Comment 20 is available at <http://www2.ohchr.org/english/bodies/cescr/docs/E.C.12.GC.20.doc>.

²² *Hoffmann v South African Airways* [2000] ZACC 17; 2001 (1) SA 1; 2000 (11) BCLR 1235.

deprived them of the help they would otherwise have received. People who are living with HIV/AIDS are one of the most vulnerable groups in our society. Notwithstanding the availability of compelling medical evidence as to how this disease is transmitted, the prejudices and stereotypes against HIV positive people still persist . . . ²³

The Court declared that people who are living with HIV and AIDS must, therefore, enjoy special protection in our law. The rationale for this is the stigma faced by people living with HIV and AIDS. As the Court explained:

“In view of the prevailing prejudice against HIV positive people, any discrimination against them can, to my mind, be interpreted as a fresh instance of stigmatisation and I consider this to be an assault on their dignity. The impact of discrimination on HIV positive people is devastating. It is even more so when it occurs in the context of employment. It denies them the right to earn a living. For this reason, they enjoy special protection in our law.”²⁴

Another area in which the law has made a noticeable intervention is in the area of treatment. With the transformation of HIV and AIDS from being an invariably fatal condition into a clinically manageable disease, a new front emerged in the battle against HIV and AIDS. This was the struggle for access to treatment.

²³ Id at para 28.

²⁴ Id.

The poor and the socially marginalised are disproportionately affected by HIV and AIDS. The cost of treatment is well beyond their means. Their lack of resources prevents them from access to health and, as a result, access to life.

Internationally, human rights law has played a key role in advancing universal access to treatment by framing treatment as a right. Indeed, one of the United Nation's Millennium Development Goals has been to secure "universal access to treatment for HIV and AIDS for all those who need it".²⁵ According to UNAIDS, most countries no longer consider human rights peripheral to their AIDS response.²⁶

In South Africa, we have shown how the law can be used to make concrete interventions in the battle against HIV and AIDS, not only in terms of the discrimination and stigma that HIV-positive persons face, but also in terms of access to life-saving medical treatment.

In the landmark 2002 *Treatment Action Campaign* (or *TAC*) case, the Constitutional Court considered the question whether government was constitutionally obliged to plan and implement an "effective, comprehensive and progressive programme" for the prevention of mother-to-child transmission of HIV

²⁵ See MDG Goal 6, Target 6b, available at <http://www.undp.org/mdg/goal6.shtml>.

²⁶ UNAIDS Report at 10. 89% of countries explicitly acknowledged or addressed human rights in their national AIDS strategies, and 92% of countries reported that they have programmes in place to reduce HIV-related stigma and discrimination.

throughout the country.²⁷ In a judgment that generated substantial interest both domestically and abroad, the Constitutional Court unanimously held that the government was indeed required, within its available resources, to progressively realise the rights of pregnant women and their newborn children to access health services to combat mother-to-child transmission of HIV.²⁸

The Court also held that the programme must include reasonable measures for counselling and testing pregnant women for HIV, and make appropriate treatment available to them for such purposes.²⁹

The significance of the *TAC* case is that it illustrates that there is a role for law to play in the fight against HIV and AIDS. As we know, the drugs used to treat HIV are manufactured by private companies and sold at prices far in excess of the purchasing power of those who need them most. Where the law places obligations on the state to promote treatment and prevent transmission, the law is operating to help prevent millions of people infected with HIV from becoming victims of – to use an economics term – “market failure”. In this way, the law makes life-saving drugs accessible to millions of vulnerable people who are infected with HIV.

The role that the Court’s decision in the *TAC* case played in helping to prevent mother-to-child transmission of the virus in South Africa is clear from the data. The

²⁷ *Minister of Health and Others v Treatment Action Campaign and Others (No 2)* [2002] ZACC 15; 2002 (5) SA 721; 2002 (10) BCLR 1033 at para 5.

²⁸ *Id* at para 135.

²⁹ *Id*.

statistic I quoted earlier, that we have reportedly achieved 95% coverage of treatment to prevent mother-to-child transmission, would likely not be had the Court not taken the decision it did in the *TAC* case. Judgment in the *TAC* case was handed down in July 2002, and by November 2004, less than 18 months later, government had committed itself to providing free universal access to ARV treatment.

Despite the positive interventions the law can make in the fight against HIV and AIDS, as seen in the *Hoffman* and *TAC* cases, the law can also intervene negatively in this fight. UNAIDS has documented how “criminalization of people living with HIV still presents significant challenges to the AIDS response.”³⁰ And even within the African Union, where a compassionate and rational approach to HIV and AIDS is so critical, there are countries whose immigration laws include either outright bans on the entry of HIV positive persons into the country³¹ or restrictions on their eligibility to stay and work.³²

I said, in my opening remarks, that advances in science must be matched by parallel advances in public policy and law. The reason I emphasise the relationship between progress in science and progress in policy and law is that discriminatory policies and laws are often motivated, at least in theory, by public health concerns. Laws that discriminate on the basis of HIV status are premised, I would argue, on a misunderstanding of where we are now in the science of HIV prevention,

³⁰ UNAIDS Report at 10. UNAIDS has documented travel bans on HIV positive persons in 51 countries, territories and areas.

³¹ For example, Sudan. While HIV positive persons are formally disallowed entry to Sudan, it is not clear if the entry ban is strictly enforced. See <http://www.hivtravel.org/Default.aspx?PageId=143&Mode=list&StateId=2>.

³² For example, Egypt and Rwanda. See www.hivtravel.org.

transmission, and treatment. In that sense, they reflect a risk assessment that is, I would venture, likely not grounded in current science. Science has long moved past the days when it was feared that HIV could be transmitted by sneezing or shaking hands, but sadly, the laws in many countries have not.

In a very recent decision by the European Court for Human Rights, in *Kiyutin v Russia*, the Court held that Russia was engaging in unlawful discrimination by refusing a residence permit to a foreign man on the basis of his HIV status. In *Kiyutin*, the state argued that its visa policy and relevant laws served to protect against “threats to national security and to the existence of humankind”.³³ The Court pointed to expert analysis of the relationship between HIV infection rates and discriminatory immigration policies as evidence of the irrationality of the law in issue. This case shows us not only how law can lag behind science, but also how science can be used by courts to invalidate the very assumptions upon which discriminatory laws are based.

My purpose is not to single-out any individual state. We must call upon all states to ensure that there is humanity and rationality in their legal systems in relation to public health, HIV and AIDS. With the advances we have made in treatment and prevention, there must be a coordinated effort to bring our laws in-line with what we currently know, not what we think we know or what we fear, about HIV and AIDS.

³³ See *Kiyutin v Russia*, ECHR (Application no. 2700/10) 10 March 2011 at para 66, available at <http://cmiskp.echr.coe.int/tkp197/view.asp?action=html&documentId=882651&portal=hbkm&source=externalbydocnumber&table=F69A27FD8FB86142BF01C1166DEA398649>.

We are not facing the same threat in 2011 as we were in 2001 or 1991, and our laws must reflect that.

CONCLUSION

Let me end by reiterating my thanks to all those involved in the ground breaking medical research that is continually being carried out. This knowledge can transform lives and societies, and we know that this work remains as urgent as ever. The laboratory is not the only front in the battle in the fight against HIV and AIDS, however. The fight against HIV and AIDS is a multi-front war that must be waged in the arenas of policy and law in addition to science.

We will not win the fight against HIV and AIDS so long as people suffering from the virus are inhibited from testing and seeking treatment for fear of the stigma and prejudice they will face if they discover they are HIV-positive. And we will not win the fight against HIV and AIDS until the poor and the most vulnerable have access to the anti-retroviral drugs they so desperately need. Science has made tremendous advances in the fight against HIV and AIDS, but only public policy and law are capable of making the interventions necessary for HIV-positive persons to live free of stigma and prejudice, and to have access to the life-saving drugs that allow them to lead normal lives.

Together, we must move past our fears, prejudices, ignorance, and immobilisation to reflect critically and creatively about the next steps we must take in order to claw-back what we have lost – which we all know to be so much – in this battle.

I thank you very much for lending me your ears, and wish you all a productive and inspiring conference.