

HIV/AIDS AND HUMAN RIGHTS: A NEW SOUTH AFRICAN STRUGGLE

When Professor Jowell asked me to give this year's John Foster Lecture, I panicked. The John Vorster I knew was a lawyer, former justice Minister and Prime Minister of apartheid South Africa. He was not only a self-avowed white supremacist who was interned during World War II for pro-Nazi activities in the Ossewa Brandwag but the apartheid Vorster was also deeply anti-semitic. He was the architect of the infamous Terrorism Act in South Africa and as a fifteen year old high school activist along with almost a hundred other youths of my age, I spent three months in solitary confinement with no access to a lawyer as a guest of John Vorster.

Jeffrey Jowell taught me of a different John Foster. One whose legal work encompassed a human rights trajectory in the tradition of my best teachers former Justice Minister Dullah Omar who died year, Justice Edwin Cameron, Geoff Budlender - arguably one of the best human rights lawyers in South Africa over the last twenty five years. A trajectory that encompasses freedom, equality and dignity for all.

I celebrate freedom. I live in a South Africa that is immeasurably better now than it was under apartheid. As a political activist of the 1976 generation, I voted for the ANC in 1994, 1999 and this year. I have also recently renewed my ANC membership. For me the ANC was instrumental in creating a democratic South Africa. My first real political reading started with Nelson Mandela and Bram Fischer's speeches from the dock. The examples of activist lawyers such as Victoria and Griffiths Mxenge who were assassinated for their anti-apartheid work in the 1980s taught me that even one of the most iniquitous legal systems could be utilised together with social mobilisation in support of human rights for all.

Today we celebrate ten years of a constitutional democracy. As you are aware our Constitution contains one of the most remarkable charters that give legal force to fundamental human rights to freedom, equality and dignity. It also imposes positive duties on the state to respect, protect, promote and fulfil the rights in our Constitution.

Next year, we celebrate the 50th anniversary of the Freedom Charter and for party activists - I am not one - the challenge must be to democratise the ANC. Democracy must be restored in a party choked by the legacy of clandestine operations when it was forced underground. The ANC must restore the fresh air of the Prague Spring by burying its Stalinist history, and by tackling the gerontocracy - the rule of old men. We welcome the capitalists to the ANC, but must equally and unashamedly pursue a social- democratic, pro-poor, pro-feminist and pro-human rights agenda, both nationally and internationally. But, I am here for a different reason.

I am a gay man (another reason I celebrate democracy). I also have HIV/AIDS. I speak to you this evening as a member of the Treatment Action Campaign. Since 1998, TAC has been involved in social mobilisation, parliamentary advocacy, litigation, treatment literacy and global solidarity work.

THE SOUTH AFRICAN HIV EPIDEMIC

The Constitutional Court echoed the South African government's description of the HIV/AIDS pandemic as "an incomprehensible calamity" and "the most important challenge facing South Africa since the birth of our new democracy." It reminded our government of its commitment to fight "this scourge" as "a top priority" because HIV/AIDS "has claimed millions of lives, inflicting pain and grief, causing fear and uncertainty, and threatening the economy". The Court said these are not the words of alarmists, but taken directly from a Department of Health strategic plan published in 2000, and from an earlier government report.¹

South Africa has possibly the most people living with HIV in the world. Every year since 1990, the Department of Health has published a survey of HIV prevalence among pregnant women attending public antenatal clinics.

In 1990 the prevalence rate was less than one percent. The most recent survey, in 2003, found a twenty-eight percent prevalence rate. Based on this finding, the Department of Health estimated that 5.6 million South Africans were HIV-positive. This is about 12% of the population.

This massive increase in prevalence over a 14-year period demonstrates the failure of prevention strategies underpinned by a lack of political will. Before 1994, the blame for this lay with the apartheid government, which cared little for an HIV epidemic perceived to be affecting mainly black people and gay men. After 1994, the failure to deal adequately with prevention was a result of the understandable, but misconceived, perception that the newly elected democratic government had more pressing matters to deal with. However, since at least 1999 the failure of prevention has been due to the ideological denial of the link between HIV and AIDS by the South African President and the consequent ramifications on all prevention efforts. This denial has been described by Justice Cameron as equivalent to the uses of holocaust denial.

Unlike most other infectious diseases, it is youth, or more accurately, young adults, who bear the brunt of the HIV epidemic. A survey conducted in 2003 by the University of Witwatersrand-based Reproductive Health Research Unit found an HIV prevalence rate of 10.2% [95% CI 9.3-11.3] among youth aged 15 to 24. Women were more than three times more likely to be infected than men. 25% of women aged 20 to 24 were HIV positive. More than 70% of youth who were HIV negative imagined that they were not at risk of infection but critically more than 62% of young people who have HIV believed that they were not at risk of infection. The HIV epidemic continues with new infections at the rate of more than 1500 per day. But, the older HIV epidemic of the early nineties has now become an AIDS epidemic. A report on causes of death published by Statistics South Africa in 2002 was compiled from a sample of death certificates. The report shows a steep rise between 1997 and 2001 in mortality ascribed to TB, pneumonia and influenza, diarrhoea and HIV.

These are all indicators of increased AIDS deaths.²

A letter by Medical Research Council researchers published in the South African Medical Journal this April explained that there had been a 68% rise in registered deaths in South Africa between 1998 and 2003. Even making

generous allowances for population growth and improved population registration, the increase in adult mortality was at least 40%. Research demonstrates that the increased registration of deaths is among young adults. The authors write "In the case of women aged 20-49 years, there has been an increase of 190% in the deaths registered which corresponds to a real increase in mortality of more than 150% once population growth and possible improvement in registration are taken into account."³

The Medical Research Council research concludes: "The uncertainty about the precise number of AIDS deaths should not allow people to dismiss the impact of HIV/AIDS on mortality. There has been a massive rise in the total number of adult deaths in the last 6 years. Given the ages at which these additional deaths occurred and the change in the cause of death profile, they can largely be attributed to HIV/AIDS. Such rises in the mortality should renew Government's resolve to implement the comprehensive plan to prevent and treat HIV/AIDS as rapidly as possible."

HIV morbidity and mortality will have severe impacts on essential services such as policing, teaching and health-care. A study carried out by the Human Science Research Council, Medical Research Council and the Medical University of South Africa found a 15.7% HIV prevalence rate among nurses in four provinces surveyed. The report states "that the HIV/AIDS epidemic has an impact on the health system through loss of staff due to illness, absenteeism, low staff morale, and also through the increased burden of patient load."⁴ Perhaps the most telling aspect of this government commissioned report, with a foreword written by the Director-General of Health, is that its release went unreported. It remained in an obscure place on the HSRC website for months, before one of the authors called the TAC in an effort to get it publicised.

Over the last six years, the TAC has campaigned to alleviate the crises in prevention and treatment. In so doing we have used many of the newly created democratic instruments of South Africa. We have used the constitution and the Constitutional Court to compel the South African government to implement mother-to-child transmission prevention. We have used the Human Rights Commission and the Commission for Gender Equality to investigate the treatment of HIV as human rights and gender equality challenges. And we have used the National Economic Development and Labour Council to try to negotiate a settlement on care, treatment and prevention of HIV/AIDS between business, labour, civil society and government. On many occasions we have presented to, and participated in, Parliamentary hearings. We used the Competition Commission to compel brand-name drug companies to drop their prices and license generic manufacturers, a story documented in detail in a publication by the AIDS Law Project, our legal representatives, entitled the Price of Life.

Our use of these institutions has not always resulted in success. Some of them, for example the Commission on Gender Equality, have been constrained by lack of maturity and a greater desire to please government than carry out their duties. Others, such as the courts, have demonstrated remarkable independence and competence. We have used these institutions with the primary aim of getting treatment to people. But we have also done this to help establish South Africa's democratic institutions, improve governance, and to strengthen the South African state. For all of these factors

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determine the competence with which a country is able to manage health crises and improve the lives of its citizens.

A STORY FROM THE MTCT PREVENTION CASE

On 11 September 2001, my friend and comrade, Sipho Mthathi and I entered the office of the Archbishop Njongonkulu Ndungane of the Anglican Church in South Africa. We went to ask him to support our struggle to ensure that women had the right and opportunity to give birth to HIV negative children through the use of antiretroviral medication.

We also went there to ask the Archbishop to visit Sibongile Mazeka, a five-year-old girl, who was dying of AIDS-related illnesses. Her aunt and foster mother, Thembisa Constance Mhlongo had provided an affidavit to the Pretoria High Court in a court case that tested science, the independence of the judiciary, parliament, medical regulatory authorities and the Chapter Institutions on the issue of the prevention of mother-to-child transmission of HIV, the virus that causes AIDS. These were the words of Thembisa Constance Mhlongo:

On 13 May 1999 I discovered that Sibongile is HIV positive, this was when her mother was admitted to hospital. I was very shocked that the child was HIV positive. I took her under my guidance because she had no one. Her mother died.

I have been up and down to the clinics with Sibongile. She attended treatment at Red Cross Children's Hospital. Since August 2000 until now she has been admitted to hospital 14 times suffering from illnesses such as pneumonia and from fits lately. On two occasions, Sibongile was admitted to the intensive care unit.

Sibongile's sickness has disturbed my work schedule. At first in 1999, I was dismissed from employment for poor attendance at work because of her sickness. In October 2000 I got a new job at the President Hotel. Again my work attendance was not good and a month ago I was warned that I don't spend enough time at work and that I am not productive at work. The point is if I want to see the doctor I can only see him in the morning so it is difficult for me to go to work.

Sibongile gets sick every day. My husband and my family are very supportive. Though I feel the burden, my family's support is my source of energy. What frustrates me now is that I can't communicate with Sibongile because she has lost her memory.

Luckily I don't get problems from my neighbours because she is HIV positive and they don't prohibit their children from playing with her.

Sibongile saw people wearing the TAC HIV-Positive t-shirt on television. She asked her foster-mother to organise a party for her with her people: "Those who sang and spoke about HIV". The TAC Gugulethu branch organised her fifth birthday party.

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To return to Bishopscourt. The Archbishop received a phone call that informed him of the unforgivable terror attack against the people of the United States of America that killed more than 3000 people in that country on that day. Simultaneously, we received a cell-phone call to inform us that Sibongile Mazeka had died.

We all mourned and continue to mourn the loss of the people who died in the United States of America on 11 September 2001. But on that day Sibongile Mazeka was only one of more than 600 people in South Africa who die every day of AIDS-related illnesses, and whose memory would be acknowledged publicly as a death caused by global injustice. In our country, in 2000, more than 40,000 children under five died of AIDS-related illnesses, reversing gains made by our government to improve maternal and child health since 1994.

Around the globe, more than three thousand people die daily in poor countries and communities of AIDS-related illnesses. People die because we do not have access to HIV/AIDS prevention, treatment and care.

Today in Africa, Asia, Central America and the Caribbean, Eastern Europe and in the ghettos of the US and Western Europe, people living with HIV/AIDS suffer local and global social inequality. We die because of excessive drug company profiteering. We die because our governments are in denial of the seriousness of the HIV epidemic by governments and bureaucratic procrastination and equivocation. We also die because men have greater access to resources and power than women because rich countries invest substantially more in war than in public goods, and because many global corporations live outside the law of global human rights. We die because religious dogma and reactionary traditionalism suppress sexual freedom and because some African leaders label homosexuality un-African. And we die because we cannot buy life-saving medicines. Unlike some of our neighbours in the north, we cannot afford buy life.

Our bodies are the evidence of global inequality and injustice. They are not mere metaphors for the relationship between inequality and disease. But our bodies are also the sites of resistance. We do not die quietly. We challenge global inequality. Our resistance gives us dignity. In the Treatment Action Campaign (TAC), the voices of our comrades, friends and children echo around the world to resist injustice. Our voices demand life even as our bodies resist death.

We celebrate resistance against apartheid and we mark the end of a regime that excluded the vast majority of black, poor and working class people from political life. The apartheid regime denied us dignity, equality and freedom. In the struggle for freedom, we used all the tools that international movements used against colonialism, capitalist exploitation, occupation, environmental degradation, injustice - marches, strikes, civil disobedience, individual and community education, courts, local and global solidarity. Music, song and poetry gave voice to our resistance.

It is a cruel irony of history that at the very moment when all the people of our country, in particular, black and working class people removed the shackles of racial oppression, and, created a free political life for all, that HIV/AIDS establishes a new apartheid. The new apartheid exists between those who can buy health and life and those who die because they are poor.

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The tools we used against the apartheid regime, we now utilise to demand the right to life and social justice for people living with HIV/AIDS globally. But, we recognise that the legitimacy of our state, and the legitimacy of our government.

TAC's litigation and civil action to compel government to implement a country-wide prevention of mother-to-child transmission of HIV/AIDS programme was undertaken to reduce the number of children who might go through Sibongile Mazeka's and her parents' experience. As my colleague Mark Heywood states, "The TAC case is an interesting one, both inside and outside of the legal proceedings. It raises important issues about the functional independence of the public service from the Executive on matters where there is political sensitivity and pressure. It suggests how human rights disputes might increasingly revolve around socio-economic rights and it demonstrates that skilful litigation can take advantage of constitutional promises."⁵

In July 2002, the Constitutional Court gave judgement in the TAC's constitutional challenge to government's policy of limiting the provision of Nevirapine for the purpose of preventing mother to child transmission (PMTCT) of HIV to a limited number of pilot sites. The judgment stated: "In finding this policy to be unconstitutional, the Court found that [t]he policy of confining nevirapine to research and training sites fails to address the needs of mothers and their newborn children who do not have access to these sites. It fails to distinguish between the evaluation of programmes for reducing mother-to-child transmission and the need to provide access to health care services required by those who do not have access to the sites."

The Minister of Health and the nine Health Members of the provincial Executive Committees (MECs) were ordered without delay to lift restrictions on the availability of Nevirapine.

This judgment followed years of meetings, negotiations and letters, as well as letter-writing campaigns, to government. Countless demonstrations took place and pressure was placed on drug companies Boehringer Ingelheim and GlaxoSmithKline to drop the prices of their antiretrovirals used to reduce mother-to-child transmission. Dozens, maybe hundreds, of workshops were conducted throughout the country by the TAC in poor communities, to trade unions, NGOs and business people explaining the science of mother-to-child transmission prevention of HIV/AIDS. On each day that the court case was heard both at high court and Constitutional Court level, massive marches were organised in major cities.

COSATU, South Africa's largest trade union and one of the three organisations making up South Africa's ruling tripartite alliance, supported the TAC at crucial moments, and joined our marches. The TAC welcomed provincial government actions that dissented from the national government's obstruction of the programme. We held night vigils outside a clinic that was given the go-ahead to implement mother-to-child transmission prevention in Gugulethu, Cape Town and cheered the government officials there who pushed the programme ahead. Thousands of TAC members living in poverty-stricken conditions with limited educational backgrounds are capable of explaining how nevirapine or other antiretroviral medicines prevents mother-

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to-child transmission prevention. So can many other South Africans as a result of the public information campaigns that the TAC ran.

In defending the MTCT case, the Department of Health claimed that it had pilot sites implementing mother-to-child transmission prevention and it wished to research the results at these sites before proceeding with a programme. This argument was disingenuous. First the pilot sites came about due to public pressure led by the TAC, courageous women and health workers. Second, the implementation at these sites was proceeding with wilful slowness. The policy's effect on mothers is described in two affidavits obtained by TAC.

Mark Heywood describes one affidavit which helped convince the Court that the pilot sites were inadequate, "In one case a pregnant woman with HIV, Sarah Hlalele, described how she had obtained a Nevirapine tablet from Chris Hani Baragwanath Hospital, sixty kilometres away from her home in Sebokeng. Unfortunately, she went into premature labour and left the tablet at home. Sebokeng hospital, where she gave birth to K, her son, had neither Nevirapine tablets nor syrup."

Today, two years after the case, the Department of Health claims over 1,500 facilities have implemented mother-to-child transmission prevention.

The programme is patchy and in many places the lack of national government will to make it work has led to sub-optimal implementation and unresolved operational problems. But in many clinics particularly in the Western Cape, Gauteng and Kwazulu-Natal the programme has advanced considerably and thousands of HIV infections are being prevented.

The MTCT case demonstrates that court action alone is insufficient. Public mobilisation on a large scale accompanying litigation led to whatever success there has been in the rollout of this programme. Undoubtedly the court was swayed by the strength of legal argument - much of it prepared by ordinary TAC members and health-care workers without legal training - that the programme would be effective, life-saving and cost-saving. But other important socio-economic judgments have also been made by the Constitutional Court with limited effect on implementation of government policy because the associated civil society mobilisation was missing or muted.

A STORY OF PARLIAMENT AND DEFIANCE OF PATENTS

In May 2000, a member of TAC, Christopher Moraka used his voice in our democratic parliament to denounce drug company profiteering and to criticise government HIV/AIDS policy. Before 1994, he would not have been able to enter that tribune of racial hate. Moraka used the example of Pfizer, a US multinational and explained that he would die because he could not afford to pay R150.00 for a single 200mg capsule of fluconazole, a drug used for common fungal opportunistic infections. Moraka explained patent laws prevented access to medicines for poor people because drug companies utilised them to profiteer. He demanded that our government use its compulsory licence powers to bring generics to our country.

Christopher Moraka died at the end of July 2000. In October 2000, we named our campaign against patent abuse, the Christopher Moraka Defiance

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Campaign. TAC went to Thailand and we imported a bioequivalent, safe and effective generic fluconazole at R1.70 instead of the R120.00 charged by Pfizer. We were prepared to go to jail against the unjust patent laws that protect multinational drug companies. Christopher's resistance, as he literally choked to death, helped save thousands of lives throughout our continent. We framed our campaign in the language, history and tradition of the ANC. But, the context and the tools have changed dramatically - the work would not have been possible without Medecin sans Frontieres, or the Thai Network of People living with HIV/AIDS, or email and global communication.

A STORY FROM THE COMPETITION COMMISSION

Christopher Moraka's wife, Nontsikilelo Zwedala used her voice and body to struggle for access to medicines for all. Everyone expected her to die before him. The prognosis was dire. Ntsiki's CD4 count was 14 (healthy CD4 = 800-1200) and her HIV viral load was 2 million. The 12 year old son of Christopher and Nontsikilelo expected to become an orphan. Nontsikilelo managed to access antiretrovirals costing R1200.00 per month through a clinical trial. Now more than three years later, Nontsikilelo is healthy, she looks after her son and earns an income as a counsellor. She was a key deponent in a complaint by Cosatu, TAC and others in 2002 to the Competition Commission against GSK and Boehringer Ingelheim. The Competition Commission and Tribunal are also new institutions created by our democracy. A direct result of the threat by the Competition Commission to demand compulsory licences forced the drug companies to reduce prices and to "voluntarily" issue licences. Today, I use the same medicines and pay R400.00 per month.

In 1998, a triple-drug antiretroviral regimen would typically cost more than R4,000 per month. Today, a South African generic company sells a triple-drug regimen to government for less than R100 per month. Private sector prices are in the region of R400 to R800 per month, depending on the regimen used. We still have work to do. One of the most important antiretroviral medicines, efavirenz, patented by MSD (whose parent company, Merck, is one of the world's largest pharmaceutical companies) in South Africa, remains, at R215.00 per month, much more expensive, even for government, than other first-line antiretrovirals. The TAC is considering applying for a compulsory licence on this medicine, especially since MSD has been unable to fill orders for it in recent weeks.

Generic companies must also be monitored. A couple of months ago it looked like there would be four suppliers of most crucial antiretrovirals in South Africa, of which three would be the generic companies Aspen, Ranbaxy and Cipla. But poor quality standards in their bio-equivalence tests have resulted in a number of important Cipla antiretrovirals being withdrawn from the market; Ranbaxy has pulled all their antiretrovirals from the South African market for unexplained reasons. We are now left in the precarious situation where Aspen is the only generic competitor supplying AZT and Lamivudine, two of the most important antiretroviral medicines. The lesson is that no corporations are to be relied on for good-will; pressure will have to be put on generic companies too.

Christopher Moraka was one of over 100,000 people in South Africa who died of AIDS-related illnesses in 2000. Queenie Qiza, and my cousin Farida Abrahams were another two. Grief, pain, rage and mourning is endured by

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families and communities - mainly poor, mainly African, mainly heterosexual, mainly women, but not only. The overwhelming majority die in silence - their disease denied a name, denied a causal connection, and smothered with silence and shame.

A STORY FROM THE PMA CASE

In March/April 2001, Joyce Ramoshaba and I together with many comrades walked the streets of Pretoria to distribute pamphlets to the public. 39 multinational pharmaceutical companies had sued the South African government because it wanted to use the law its democratically elected Parliament enacted, its social-democratic Constitution mandated, and to use World Trade Organisation recognised provisions in the TRIPS Agreement to make medicines more affordable. Joyce Ramoshaba worked together with thousands of people in our country. She helped mobilise tens of thousands of people across the world to say in one voice:

No to drug company profiteering.

Global solidarity and internationalism was central to the victory against the drug companies. People from every continent demonstrated against GlaxoSmithKline, Pfizer, Bristol Myers-Squibb, Boehringer Ingelheim, Aventis and other drug companies. We resisted the global pharmaceutical industry. Mediciens sans Frontieres, ACT-UP, Consumer Project on Technology, ACTS A, Oxfam were joined by activists in Brazil, Philippines, Thailand, USA, Britain, France, Nigeria, Burundi, Namibia, Sweden, Netherlands, Kenya, Japan, Australia and everywhere. The drug companies lost and the world won the Doha Agreement. Joyce Ramoshaba celebrated and continued to use her voice. She died because she started anti-retroviral therapy too late. Her obituary written by her comrade Sharon Ekambaram gives a small glimpse of her life.

Joyce Moloko Ramoshaba was born on the 11th of August 1964 in Polokwane.

In 1996, after being diagnosed HIV positive, Joyce joined hands with 60 other women in Garankuwa Northwest of Pretoria, to form a support group which then give birth to Positive Women's Network. ... Joyce had been a strong member of ANC Women's League; she worked with Gauteng Partnership, Grassroots AIDS Action, Treatment Action Campaign, and AIDS Consortium amongst others. Joyce was 1 of the 2 survivors from the 60 women who started Positive Women's Network. She became ill and died on the morning of 6 February 2004. Joyce lost her husband to AIDS some years ago and she is survived by her only son Kamogelo whom she loved dearly.

The case against the Pharmaceutical Manufacturers Association began in 1997, when the South African Parliament passed the Medicines and Related Substances Control Amendment Act. This Act introduced provisions compelling pharmacists to substitute brand-name off-patent medicines with more affordable generic ones, and to import medicines from wholesalers in other countries if they offered better prices than pharmaceutical companies offered inside South Africa, a provision known as parallel importation. The Act also provided for the establishment of a drug pricing committee. These provisions are standard in Canada and many European countries, which go further than the South African law in some respects.

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The pharmaceutical companies, represented by the Pharmaceutical Manufacturers' Association (PMA), litigated against the act, particularly using the rights to property clauses in Chapter 2 of the Constitution. This was ironic because the Constitution was meant to be used to enforce the rights of poor people. Mark Heywood summarises, "On the international arena the PMA's affiliates unleashed a barrage of 'conglomo-talk', alleging that the actions of the South African government threatened the international patent regime, encapsulated by the TRIPS agreement, and that the government's action made it a pariah state acting contrary to its obligations as a member of the World Trade Organization (WTO) . Initially this lobbying had some success, particularly in the USA where it led to SA being placed on a US Trade Representative (USTR) 'watch list' and became one of the subjects of bi-lateral discussions between the SA and US governments. This action was successfully contested internationally, particularly by groups such as ACT-UP and the Health-Gap Coalition. In South Africa, the success and impact of these arguments began to suffer a reversal when in January 2001 the Treatment Action Campaign (TAC) announced that it would seek permission from the Court to join the case as amicus curiae. The legal papers filed by the TAG as amicus applicant, became the new focus of the case. In TAG's hands the litigation brought by the PMA became an instrument for progressive and people-driven advocacy and mobilisation. Its legal papers offered an opportunity, in the glare of international media, to investigate and debunk the 'conglomo-talk', Despite PMA opposition, TAG was admitted as amicus curiae on March 6th 2001, and the PMA was instructed to respond to the allegations and arguments about 'Justification' made in the TAG Founding Affidavit. The case collapsed on April 19th 2001, leaving the South African government free to implement the Act."

The case had repercussions beyond South Africa's borders. The global demonstrations organised to coincide with it raised awareness around the world of the disparities in access to medicines between rich and poor countries, and the tactics pharmaceutical companies used to increase their hegemony. It would be an exaggeration to say that the tide has turned, but there have been gains by developing countries as a result of the case. For example, Thai activists managed to get a patent on a Bristol-Myers Squibb antiretroviral overturned; Kenya implemented legislation to increase access to generic medicines; and many developing countries have taken steps to access generic medicines, the last example aided by the success of the Brazilian antiretroviral programme.

We had to transform the old slogan: "Mobilise! Don't Mourn" into "Mobilise and Mourn". We had to learn law, epidemiology, science, mathematics, medicine, pharmacology, ethics, political economy, and international relations.

In 2004, Chief Buthelezi a former collaborator with the apartheid state and then a Minister in the first two democratic Cabinets re-enters the political field of vision. He tragically buried two of his children within three months of each other this year and declared that they had died of AIDS-related illnesses at their funerals. He followed the Sisulu family, who declared that their niece had died of AIDS-related illnesses, and the family of Graca Machel who placed an advert in Noticias stating that the brother of former President Machel had died of AIDS. Former President Mandela declared that unnamed members of his family had succumbed to HIV/AIDS.

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Over the last five years, two legendary leaders of the ANC Youth League, Parks Mankahlana and Peter Mokaba died of AIDS-related illnesses. Themba Khoza, the leader of the Inkatha Youth Brigade also died of AIDS-related illnesses. But despite hidden knowledge at every level of the ANC of their HIV infection their deaths and funerals were shrouded in denial.

A STORY OF OPENNESS AND CIVIL DISOBEDIENCE

Not so with our comrade Edward Mabunda, a poet, father, brother and husband. In January 2003, he attended the TAC NEC meeting in Johannesburg and on 14 February 2003, he recited a poem in front of our Parliament as close onto 20,000 people marched to demand a national treatment plan as President Mbeki devoted 38 seconds to HIV/AIDS in his address. Edward Mabunda was disappointed that he could not lead the civil disobedience campaign that commenced on 20 March with the occupation of the Sharpeville, Cape Town and Durban police stations demanding the arrest of the Minister of Health and the Minister of Trade and Industry or the arrest of all the civil disobedience volunteers. He was in hospital. He died during the TAC Civil Disobedience Campaign. Mark Heywood writes of Edward Mabunda:

“The funeral of a TAC leader, Edward Mabunda, on April 19th 2003, was symbolic of the conflicts and contradictions of President Mbeki’s HIV/AIDS policy.. Mabunda was a respected ANC leader in the Winterveld area. However, in the last years of his life the ANC had no internal space to admit his - or others’ - HIV infection. Therefore Mabunda’s last years of social activism found support in and expression through TAC. When in early 2003 Mabunda became increasingly sick with HIV related illnesses, he had to travel 90 kms for medical attention at Johannesburg General Hospital, getting assistance from TAC leaders such as Pholokgolo Ramothwala.

With support from the ANC for his illness Mabunda might have found this support closer to home. Instead he died at the Johannesburg Hospital visited in his last hours by leaders of TAC and COSA TU but, despite the publicity surrounding his illness, not the ANC. Nonetheless, the Winterveld ANC branch and local ANC councillors, including the Mayor, rushed to reclaim him in death. Attempts were made to hijack his memorial service and funeral on April 17th by playing down his HIV infection and his association with TAC. However his mother and wife resisted this and a jointly organised funeral was agreed upon.

Mabunda’s funeral was the first public funeral that openly linked an individual’s death due to AIDS with membership of the ANC. Attended by over 1000 people, TAC’s T-shirts, ‘Wanted’ posters and posters of Mabunda proclaiming ‘Why Civil Disobedience is Necessary’ flew alongside ANC flags. ANC, COSA TU and TAC leaders addressed the funeral service. After the service a large convoy wound its way through the township to the grave. But despite this formal rapprochement, after Mabunda’s body was lowered into the grave, ANC Youth League members threatened violence against TAC activists as they were leaving the township.

Edward Mabunda and other comrades helped reverse the biggest failure of ANC policy and practice in the first decade of our democracy. On 8 August 2003, Cabinet instructed the Health Minister to develop an HIV/AIDS anti-

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retroviral treatment plan and to implement it with urgency. Mabunda and many of our deceased and dying comrades helped achieve a shift in budgetary resources that will be measured in billions of rands over the next decade to save the lives of millions through the treatment and prevention of HIV/AIDS.

The civil disobedience campaign was ultimately successful because it helped achieve a change of government policy, but it was a difficult time for the TAC. Our closest ally, the Congress of South African Trade Unions (COSA TU) refused to participate in the campaign, claiming that it challenged the legitimacy of the government. And indeed, this was the main argument offered against the civil disobedience campaign from a variety of media commentators and government itself. It is an argument which fails to recognise the tradition of civil disobedience in democracies and its theoretical underpinnings.

The TAC civil disobedience campaign was aimed at a particularly unjust policy of non-action that allowed thousands to die a preventable death. The civil disobedience actions were non-violent but involved actions for which those participating in them were prepared to accept the consequences. Participants had to be over 18 years old and had to sign consent forms explaining that they understood the consequences of civil disobedience.

This consent form raised the ire of one anti-apartheid activist who argued that when he committed civil disobedience under apartheid he never had to sign a consent form. He failed to understand that when civil disobedience is committed against a legitimate state, the forethought and preparation for it had to be on a much greater scale than under the illegitimate apartheid government.

The civil disobedience campaign resulted in a number of TAC members being beaten up by Durban police who were motivated more by racism than the horror at the occupation of their station. Eighteen TAC members were arrested for sitting in the Department of Trade and Industry offices in Cape Town. They spent a few hours in police cells before being charged, but after numerous court appearances the charges were dropped. It is worth noting that the Cape Town police acted with great professionalism and restraint during the campaign, with some officers even expressing sympathy for the cause. AIDS affects the police too.

A DISCUSSION OF ERROR

In April 2004, in a pre-election interview with the *Mail* and *Guardian*, Sankie Makhanyele Mthembu, the deputy secretary general of the ANC, was the first senior leader of the ANC to publicly admit to a mistaken approach to HIV. Asked whether she felt that the party had been 'damaged by its handling of HIV/AIDS' she replied:

"The debate in the ANC took place in the context of the entire world struggling to deal with the epidemic; it was a trial-and-error situation. The people understood this, there was no backlash on the ground.

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I don't think being wrong on an issue necessarily damages an institution - people make mistakes and misjudge. The important thing is to say: 'We were wrong, now we must take the correct route.'"

This concession, whilst welcomed, covered up in a few sentences as a 'mistake' an approach that caused great loss of life and dignity, as well as the failure of South Africa and Africa's attempt to contain the epidemic at a critical period. In his introduction to *Proletarian Science? The Case of Lysenko* written by Dominique Lecourt, Louis Althusser speaks of the privileged role that Lenin allotted to error in the "process of the rectification of knowledge."

According to Lecourt, Lysenko's science hailed by Stalin as the triumph of proletarian over bourgeois science, "signalled no more nor less than the death sentence to genetics in the Soviet Union: all teaching of this discipline and all research were to be prohibited for more than fifteen years. Knowing the developments this science saw in the 1950's, knowing the extent to which it has given rise in medicine, physiology, agronomy... one can imagine the disastrous consequences of these administrative measures which amazed the whole world." Lysenko attributed the "victory" of his idiosyncratic theories in the biological sciences to "the interest taken in it by the Party, the Government and Comrade Stalin personally."

Thousands of scientists were persecuted in the Soviet Union because Lysenko found favour with Stalin. Soviet biological science stalled for perhaps thirty years.

There are a few rivals to Lysenko's position in the South African AIDS debate. I wish to give this dishonourable achievement to Anthony Brink an AIDS denialist who seems to have found the ear of the President. South African scientists, like Hoosen Coovadia and Malegapuru Makgoba have also experienced the ire of the President, but while South African scientists will not be shot or sent to Siberia, the cost in lives will arguably exceed that caused by Stalin's delusion.

I return to the transition. In 1994, the first democratic government of President Mandela adopted the National AIDS Plan devised with civil society, business, the labour movement and all political parties under the banner of NACOSA. This plan was based on the best practices throughout the world. Its inter-disciplinary approach combining an understanding of poverty, inequality, racism and discrimination with prevention, treatment and care was undisputed.

Minister Nkosazana Zuma developed the boldest vision for health care reform. She challenged religious dogmatists by affirming women's right to choose with the CTOP Act. She created a framework for the outlawing of tobacco in public places. Medical Schemes utilised as the chief instruments of privatisation of health care were required to conform to principles of solidarity rather than profit and risk-rating. Primary health-care was prioritised. An essential drug list was created. The first modern attempt to eradicate tuberculosis was undertaken. Maternal and child health care was prioritised. Drug company profiteering was tackled through generic substitution and other measures to make medicines affordable. The HIV/AIDS budget was increased from R20million to R70 million. Condom provision was increased from 1 million to 10 million.

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The impact of fiscal discipline undermined the efficacy of these structural reforms and impacted negatively on the quality and affordability of health-care in the public and private sectors.

A legal and human rights framework against HIV discrimination in schools, workplaces, health care and social services was developed.

In 1997, the ANC's 50th National Congress passed a resolution that noted that HIV/AIDS would "massively impact on the economy, will impact socially with more orphans and the loss of breadwinners, and on the health service with additional new users" and demanding that the HIV prevention: "campaign be led by the President of our organisation who must direct that the NEC, Branches, the Youth League, the Women's League throughout our Provinces to place the campaign against AIDS on their day to day agendas" .

Anyone could have predicted the impact of monetarist policies in health on HIV/AIDS. On 1 March 1999, Professor Ron Green-Thompson the KwaZulu-Natal Health Superintendent General reported that more than 40% of patients admitted to Durban's King Edward hospital had contracted HIV. He also pointed out that 32.6% of women attending the antenatal clinic at King Edward had HIV or AIDS. Most significantly, he reported a reduction of more than R500 million in the health budget's shortfall over the previous period and stated that the health department's staff had been reduced from 52 188 in October 1997 to 50 229 by March 1999. (Source: *Business Day* 02 March 1999).

There has been a tendency towards over-centralisation rather than co-ordination of policy-making in President Mbeki's office. One of the most damaging interventions in this vein was the creation of the Presidential International Advisory Committee on AIDS. The error, deceit and disingenuity that emanates from government from this intervention poses a challenge to civil society, democracy and our institutions of governance.

One day a tragic history will be written. Now we are still living it.

President Mbeki has never had the courage to state in open and public forums that HIV does not cause AIDS. He has done so in private to scientists, to the ANC NEC, to the ANC parliamentary caucus and to anyone he assumed to be an ally. But, this lack in public candour resulted in policy confusion, denial and unnecessary conflict between civil society and government. And, it has damaged the ANC.

Bodies such as the Medicines Control Council, the Medical Research Council, Stats SA, the Human Rights Commission, Parliament and other agencies were pressured to adopt an HIV denialist agenda.

On 19 November 2003, the Minister of Health unveiled an operational plan for responding comprehensively to the HIV epidemic. The plan included numerous welcome provisions, including rolling out antiretroviral treatment to the country's 53 districts by the end of this year and increasing the number of public health-care workers by over 22,000 by 2008. The policy change of August/November 2003 marked a qualitative shift in programme and resource allocation. We hoped that reason had prevailed and maybe it has.

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But to date, instead of over 50,000 people on anti-retroviral treatment by March this year as promised in the Operational Plan released by government, fewer than 15,000 are on treatment as of November, 2004.

The implementation timetable of the operational plan, although referenced numerous times in it, has never been published.

Consequently, the TAC's current campaign is centred around access to information. On 20 February we asked for this implementation timetable. We then followed this up with numerous requests. There was no response, despite the Constitutional right guaranteeing access to information, enacted by the recently adopted Promotion of Access to Information Act.

Left with no options, we have proceeded with court action to obtain the timetable. The first response to our requests came in government's court papers in September, where it was stated that the timetable alluded to in the treatment plan was a draft and that the numerous references to it were all errors. This is an unlikely story and it is tragic that government official risk perjuring themselves because of the Minister of Health's incompetence, but we cannot yet prove this in a court. We therefore decided to request only punitive costs for government's delayed response in a court case that took place on 4 November.

We are proceeding with separate litigation to compel government to make the timetable available, litigation that could be ended instantly simply by the Minister of Health providing the requested information.

The struggle for access to treatment is global and demonstrates how modern technologies, such as the internet, can facilitate international campaigns and solidarity. There have been tangible results. The Global Fund to Fight AIDS, TB and Malaria is a crucial mechanism for ensuring that developing countries can finance treatment and prevention programmes for these three diseases. It owes its existence to activists across the United States and Europe such as Health-GAP, Act-Up, MSF, Treatment Action Group and Gay Men's Health Crisis, as well as Kofi Annan and a group of academics lead by Jeffrey Sachs who penned the ground-breaking Harvard Consensus Statement. There is still much to be done. Drug prices remain too high for many diseases and in all countries. The Global Fund is terribly short of the money it needs to ensure the World Health Organisation's goal of three million people on treatment by the end of 2005 is met. The United States government, through its PEPFAR fund, is financing the growth of stigma and the failure of prevention by promoting an ideologically based abstinence-first policy that has already been shown not to work. All these challenges can only be overcome through continued global solidarity. This is the true challenge of globalisation and the benefits which it can bring.

¹ HIV/AIDS & STD strategic plan for South Africa 2000-2005 and an earlier report to which it refers.

² HIV and Sexual Behaviour Among Young South Africans: A national survey of 15-24 year olds. Reproductive Health Research Unit of the University of the Witwatersrand. Published by Health Systems Trust, 2004.

³ Statistics South Africa, 2002, Causes of death in South Africa 1997-2001 Advance release of recorded causes of death. P0309.2. Debbie Bradshaw, Ria Laubscher, Rob Oorrington,

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⁴ Shisana, O. et al. The Impact of HIV/AIDS on the Health Sector: National Survey of Health Personnel, Ambulatory and Hospitalised Patients and Health Facilities, 2002. HSRC, MRC, MEDUNA.

⁵ Heywood, M. 2003, Preventing Mother-to-Child HIV Transmission in South Africa. SAJHR (19) 2003, pp. 278- 315.

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