

## **Martin Delaney Lecture**

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**A journey into community involvement in translating HIV  
research into prevention and treatment programmes:  
past, present and future struggles in South Africa**

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SECTION27, incorporating the AIDS Law Project**

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Good afternoon,

It is indeed a great honour and privilege to be able to speak to you today. Unfortunately I never had the opportunity to meet Martin Delaney, who died a little over two years ago on 23 January 2009 aged only 63. Upon his death, Project Inform – the organisation he founded in 1985 – paid tribute to his contribution:

When the final history of AIDS is written, there is no question that Martin Delaney will be one of the key figures who brought this great human tragedy to an end. ... The fact that we now benefit from a very strong arsenal of medications to treat HIV infection, and from information about how to use them effectively, is largely attributable to this great man.

The inaugural Martin Delaney Lecture was delivered last year by Lynda Dee from AIDS Action Baltimore and the AIDS Treatment Activists Coalition. Lynda focused on the accomplishments of community treatment activism in the US since 1985. She spoke about Martin's contribution to community activism, scientific research and treatment access, describing him as "the beloved originator of the community treatment activist movement". It is fitting that this lecture is given in his honour.

### **Overview of the presentation**

In this talk, I will focus on South Africa's response to the HIV epidemic spanning almost three full decades. In particular, I will look at how the community – social movements of people living with HIV; community-based organisations; public interest law firms – "engaged" with those who exercise public and private power to ensure access to much-needed prevention and treatment interventions.

Because of time constraints, I will only focus on the prevention of mother-to-child transmission of HIV (PMTCT), highly active antiretroviral therapy (HAART) and medical male circumcision (MMC). In addition to this focus on key community responses, I will also consider a brief history of the South African epidemic and a snapshot of HIV in South Africa today. To end, I will draw on the lessons of our recent past to consider the role of the community in South Africa going forward.

### **Three hypotheses**

Before I begin with History 101, it's important to set out my three hypotheses: or in legal-speak, my three foundational principles: first, science matters; second, rights matter; and third, community is key. Using my focus on three key community responses – PMTCT, HAART and MMC – I plan to show how these three principles are central to translating HIV research into prevention and treatment programmes.

What do I mean when I tell a group of scientists that "science matters"? For those trained in basic science or clinical research, it may seem quite obvious that public health programmes should be evidence-based. But in the world of policy-making, resource-allocation and political manoeuvring, much often gets lost in translation. One needn't look beyond the US for examples: think about the lack of federally-funded needle exchange programmes under Clinton and beyond; and the Global Gag Rule under Reagan and Bushes 1 and 2.

What about rights? In my world, human rights include civil and political rights (such as the right to vote and freedom of the press), socio-economic rights (such as the right to have access to health care services), and positive and negative obligations – primarily (but not exclusively) imposed on the state – regarding their realisation.

Yes, my world is Sarah Palin’s “socialist” nightmare – a world where the state is under a legal duty to take all reasonable measures, within its means, to see to it that access to HIV prevention and treatment services is not dependant upon race, class, gender, sex, sexual orientation, nationality or geographic location.

Left to its own devices, the state will be unable and/or unwilling to go the full nine yards – because of conflicting political and commercial pressures; because of competing resource demands; and often because of a lack of capacity. As we are constantly reminded: “Never attribute to malice that which can be adequately explained by stupidity.” Or as the English say: “Cock-up before conspiracy”.

Enter the community. But where exactly does it fit in? I can think of at least five overlapping and mutually supporting areas (which I consider again later):

- Protecting people’s rights;
- Holding stakeholders to account;
- Influencing the scientific agenda;
- Popularising science; and
- Translating scientific developments into policy and programmes.

### **Brief history of the South African epidemic**

AIDS was first reported in South Africa in 1982. As was the case in the developed world, the early South African epidemic was concentrated, being associated mainly with gay men, blood transfusion recipients and hemophiliacs. But in the early to mid 1990s, it became clear that the epidemic had also become generalized, with various studies confirming that HIV had already entered the general population by 1989.

The first reported AIDS deaths were described as “isolated cases”. Government said there was no need to panic – only gay men were at “high risk”. In 1987, new regulations provided for foreign nationals with HIV to be denied entry to and/or be deported from the country. A year later, 1000 foreign mineworkers with HIV were repatriated. Two years earlier, a survey found a 0.02% prevalence of HIV amongst local mineworkers; amongst those from Malawi, it was 3.76%.

The early 1990s witnessed a significant shift. Shortly after its unbanning in February 1990, the then-exiled African National Congress (ANC) – now the ruling party – hosted a health conference in Mozambique. Chris Hani, a senior South African Communist Party and ANC leader, warned against “allow[ing] the AIDS epidemic to ruin the realization of our dreams.” He correctly predicted that if left “unattended”, the epidemic would “result in untold damage and suffering”. Hani was tragically assassinated three years later.

The ANC thereafter worked closely with the Department of Health to set up the National AIDS Convention of South Africa (NACOSA), an umbrella body to co-ordinate the country's response. In late 1993, just months before South Africa's first democratic elections and the coming into force of its first Bill of Rights, the country's highest court (at the time) recognized the right of people living with HIV to medical confidentiality. But at the same time, HIV prevalence amongst antenatal clinic attendees mushroomed – from an estimated 0.7% in 1990 to 7.6% in 1994.

Within months of President Mandela's government taking office, the NACOSA AIDS Plan – which included a focus on law and human rights – was adopted as official policy. A new HIV/AIDS directorate in the Department of Health sought and received assistance from the AIDS Law Project (ALP) – now SECTION27 – on the implementation of a rights-based response. Numerous court decisions and legislative developments gave substance to the new constitutional protections against unfair discrimination and unjustifiable limitations of the right to privacy.

The rumblings of dissatisfaction, however, had also begun. In 1996, the Department of Health's funding of the musical *Sarafina II* – with deeply flawed HIV prevention messages – came under fire, primarily because public sector tender processes had not been followed. This was followed shortly thereafter by the "Virodene" scandal, which saw official Cabinet support for an alleged cure for AIDS – later determined to be a toxic industrial solvent – that had been tested on human subjects without the approval of the relevant drug regulatory authority.

Mandela, who – like Bill Clinton – became increasingly outspoken on HIV/AIDS after leaving office, has admitted that he could and should have done more when in power. It was during his presidency when HAART became the standard of care in the developed world; and when research proved that ARV medicines were effective in preventing transmission of HIV from mother-to-child.

In a speech delivered in Parliament in October 1999, just months after coming into office, former President Mbeki began his public questioning of the causal link between HIV and AIDS. Early the following year, he established an international AIDS advisory panel tasked with – amongst other things – advising him on whether in fact HIV causes AIDS. The panel, composed of equal numbers of "orthodox" scientists and denialists, reached a predictable deadlock.

The evidence shows that Mbeki supported the position of the denialists and that powerful elements of denialism continued to bedevil the country's response to the epidemic throughout his presidency. A 2008 study published by Chigwedere et al conservatively estimates the cost of denial in South Africa at over 330,000 lives. To this day, Mbeki has not apologised. To the contrary, he has made it clear that his only regret was being forced to disengage from the "debate".

### **Key community responses**

Before looking at my three identified areas of focus, it's important to sketch further the context within which the community operated.

First, government's official plan to respond to the epidemic – the HIV/AIDS/STD Strategic Plan for South Africa 2000-2005 – contained no commitment to providing comprehensive PMTCT (or HAART) services. Jonathan Shapiro (aka Zapiro), a political cartoonist who has documented the struggle for an evidence-based response in South Africa, says it all with his blank canvas.

Second, post-Apartheid South Africa is built on a set of foundational values, including supremacy of the Constitution and the rule of law. In addition to entrenching access to health care services as a fundamental right, the Constitution also requires the state to “respect, protect, promote and fulfil” all rights. In particular, section 27 requires the state to “take reasonable legislative and other measures, within its available resources, to achieve the [right's] progressive realization”. All rights, and the obligations they impose, are judicially enforceable.

In short, there was a severe disconnect between what the state was actually doing and what the Constitution required it to do. The community saw its role as ensuring that the chasm was bridged. The Constitution provided the cover to advocate, engage, protest and picket, as well as the tools to force the state's hand on policy.

### PMTCT

A number of scientific developments in the mid- to late 1990s indicated that ARV medicines could be used to reduce the risk of transmission from mother-to-child. Successful clinical trials of simplified regimens in 1998 and 1999 meant that PMTCT programs could be implemented in resource-poor settings, completing the evidence base necessary for translating science into appropriate policy and programmes.

The state's initial response to the AZT data was positive: a commitment to establishing pilot sites in Gauteng. But soon thereafter, citing the high costs of AZT, the plan to begin operational research was dropped. In April 1999, government committed to “nam[ing] an affordable price for the implementation of AZT” for PMTCT and reporting within six weeks on related issues. In turn, the Treatment Action Campaign (TAC) agreed to put pressure on Glaxo Wellcome to reduce its prices. Only TAC kept its part of the bargain.

At the same time that community advocacy was creating the conditions for PMTCT and HAART programmes, denialism was taking hold at the highest levels of government. In September 1999, the new health minister told TAC that government was committed to a PMTCT program, but that there were concerns about the safety and efficacy of nevirapine. A month later, the new President questioned the link between HIV and AIDS in his address to the upper house of Parliament.

Bowing to community pressure, government announced – in August 2000 – that nevirapine-based PMTCT programs would be considered once the drug was

registered for the purpose in South Africa. The catch was that the drug would be used for two years at a limited number of “pilot sites” around the country. There was no commitment to doing anything more. In fact, the policy imposed an effective ban on the provision of PMTCT services at all other public sector sites.

With litigation at the heart of its intervention, TAC launched a multi-media public campaign that was supported by treatment literacy and community organization and mobilization. The roots of the campaign had been firmly planted three years earlier when a coalition – including the ALP, the AIDS Consortium and the Perinatal HIV Research Unit at Wits University – began lobbying government to urge the creation of a national policy on and programme for PMTCT.

On 21 August 2001, TAC filed its high court application along with two other plaintiffs: the Children’s Rights Centre in Durban and a coalition of concerned paediatricians known as “Save Our Babies.” Just over eight months later, following a series of high court decisions on various aspects of the case, the matter reached finality at the Constitutional Court. On 5 July 2002, the country’s highest court found in favor of TAC, squarely rejecting each of the government’s arguments.

In a unanimous judgment the Court ordered the state to permit doctors to prescribe nevirapine in state clinics and hospitals; to provide nevirapine to those state facilities with adequate capacity to implement PMTCT programmes; and to take “reasonable measures” to expand testing and counseling programs in the state sector to facilitate the use of nevirapine for PMTCT. All this was to be done “without delay”.

#### HAART

The political and symbolic significance of the Court’s decision in PMTCT cannot be overemphasized. It dealt a decisive blow to denialism within government, and paved the way for TAC’s next major campaign: compelling the state to develop and implement a nationwide HAART programme free to users of the public health system at point of service. That campaign, also supported by treatment literacy and community organization and mobilization, was infinitely more complex.

Underpinning the need for the campaign were a couple of uncomfortable truths:

- First, the HAART breakthrough announced at the International AIDS Conference in Vancouver in 1996 had little meaning to people with HIV in the developing world – the drugs were simply too expensive for them or their governments to afford; and
- Second, for those with access, HIV was being transformed into a chronic manageable condition; for those without access, it remained a death sentence.

Put differently, life was up for sale.

While denialism may have been the overriding factor influencing the South African state’s non-response, TAC could not limit its interventions to government inaction

alone. For example, it was also compelled to take direct legal and other action to bring down the prices of key ARV medicines, as well as to make out an economic argument in favour of providing HAART in the public health sector.

Central to the drug pricing leg of the campaign was the antitrust complaint lodged by the ALP in September 2002 against GSK and Boehringer Ingelheim – on behalf of TAC, individuals living with HIV, health care providers, the largest trade union federation in the country and one of its affiliates, and the AIDS Consortium representing a network of AIDS service organizations.

The complaint alleged that the companies' conduct in charging excessive prices for AZT, 3TC and nevirapine products was "directly responsible for premature, predictable and avoidable deaths of people living with HIV/AIDS". The Competition Act of 1998, interpreted in the light of the constitutional guarantee of access to health care services, was the legal instrument of choice.

The *Hazel Tau* case, named after the first applicant in the matter, was ultimately settled. In exchange for the complaint's withdrawal, the companies agree to grant multiple licences to generic companies – on reasonable terms – to bring single agents and fixed-dose combinations (FDCs) to market, as well as to permit locally manufactured products to be exported to all sub-Saharan African countries.

Drug prices have since plummeted. At the time the complaint was lodged, a month's supply of 3TC alone cost R912 ( $\pm$ US\$125) in the private sector. Today, the cheapest generic in the private sector retails at just R44.40 ( $\pm$ US\$6.10) – representing a price reduction of 95%. In the public sector, the drug is procured by the state for less than half the lowest private sector price.

A second leg of the campaign, which focused on the economics of providing access to HAART in the public sector, involved close collaboration between TAC and the University of Cape Town's AIDS and Society Research Unit. Put simply, that research showed that while the provision of HAART may not have been cost-saving, it was nevertheless cost-effective – on condition that the drug bill could be reduced.

Ultimately, however, the major stumbling block – the state's ideological (and irrational) opposition to HAART – had to be addressed squarely. On 14 February 2003, just before the State of the Nation Address, TAC led a march of thousands to Parliament to demand treatment. Permission to use an image of Nelson Mandela wearing a TAC t-shirt on the official march poster was both sought and obtained.

On 20 March 2003, TAC launched its campaign of civil disobedience with marches in three cities: Cape Town, Durban and Sharpeville. March 21<sup>st</sup> is Human Rights Day in South Africa, commemorating the gunning down of unarmed protestors at the Sharpeville Police Station in 1960. All three marches culminated in the laying of criminal charges against two Cabinet members.

The ministers were targeted for having failed to stop “600 HIV/AIDS deaths every day” – the Minister of Health for obvious reasons; and the Minister of Trade and Industry for failing to use his statutory powers to facilitate the market entry of generic ARV medicines. Arrests of protestors – but not the Ministers – were made in Durban and Cape Town. Kebareng Mokoetsi, the woman who is pictured at the rally in Sharpeville, died a week later of AIDS.

There isn’t sufficient time to describe the events that unfolded thereafter. Suffice it to say that on 8 August 2003, Cabinet decided that “the Department of Health should, as a matter of urgency, develop a detailed operational plan on an antiretroviral treatment programme”.

On 19 November 2003, Cabinet adopted that plan, with HAART as one of its core components. It would take the threat of further litigation some four months later before implementation of the plan began and the state started to provide HAART to users of the public health system.

### MMC

In the post-Mbeki era, HIV-related policy processes have largely been evidence-based. And then there’s medical male circumcision (which had its roots in the denialist era)! Despite the overwhelming evidence obtained in three trials – in South Africa, Kenya and Uganda – and the observational data that gave rise to the hypothesis underpinning them, policy makers in South Africa were paralysed.

What followed was a policy “merry-go-round”, which gave rise – in the name of consultation – to a never-ending discussion amongst and between civil society sectors. The science seemingly did not matter: instead, all views – including those ideologically and culturally opposed to male circumcision – were given equal space. It was not a debate about how to implement public sector programmes in a culturally sensitive manner, but rather whether to implement at all.

TAC and its allies worked to create the basis for actions necessary to break the inertia. At the policy level, community activists ensured that the National Strategic Plan 2007-2011 called for policy development and programme implementation. The frustrating debate within various structures of the South African National AIDS Council (SANAC) was escalated to the body’s plenary. Behind the scenes discussions indicated the need for a “political solution”.

The tipping point was King Goodwill Zwelethini’s revival of the practice of male circumcision as an integral part of Zulu initiation rites. Abandoned much earlier by King Shaka because of its negative impact on the combat-readiness of his troops, the King announced that the custom was to be brought back. Importantly, his intervention demonstrated that culture is not static and can indeed develop to accommodate changing circumstances.

The MMC programme is being implemented at a remarkable pace, especially in the province of KwaZulu-Natal (KZN) – the epicenter of South Africa’s HIV epidemic. Of



concern, however, is the widespread use of the Tara KLamp – an unsafe medical device that was developed with infant circumcisions in mind. For the record, medical devices are not yet subject to regulation in South Africa.

There is no good scientific or programmatic reason why the device should be used. Suspect state procurement processes suggest that its use is commercially motivated. TAC and its partners are considering their next steps – engagement with the political leadership of the province has apparently reached a dead-end.

### **Snapshot of HIV in South Africa today**

The end of state-sponsored denialism and the embrace of evidence-based policy making and programming has come particularly late in South Africa's epidemic:

- Amongst public sector antenatal clinic attendees, HIV prevalence rates range from 16.9% in the Western Cape to 39.5% in KZN – from 9.5% in the West Coast District in the Western Cape to 46.4% in Uthukela District in KZN;
- Amongst sexually active adults aged 15-49, prevalence rates range from 5.3% to 25.8%, averaging out across the country at 16.9%; and
- The highest prevalence rates amongst women are in the 25-29 age group – men reach a lower peak more gradually and later.

Change may have come late, but it has come strong. The public commitments of the President, his deputy, and the Minister of Health and his director-general have been accompanied by budgetary increases and the scale-up of service provision. But SANAC remains largely dysfunctional, and the legacy of denialism still undermines the country's response – too many of the old guard remain in their positions, and the "capacity deficit" is proving particularly difficult to address.

In terms of its research and civil society communities, however, South Africa remains strong:

- It is home to a number of world-renowned researchers and institutions;
- It is a world-leader in large-scale clinical trials – these include the CHER study on early infant HAART initiation; the Orange Farm MMC trial; and CAPRISA 004 on the use of 1% tenofovir gel as topical PrEP; and
- Its civil society leaders, in addition to continuing to hold the state and the private sector to account, participate in a range of governance structures and provide advice on an ongoing basis to key government departments.

### **Role of the community going forward**

So what about the role of the community going forward? Looking back, we can see quite clearly what has – and has not – worked. In my view, the following elements should continue to underpin the community response:

- A primary focus on protecting people's rights, whether as people living with HIV, as people vulnerable to HIV infection, or as research subjects;
- Influencing the scientific agenda;

- Popularising science, including building support for evidence-based policy-making and programming; and
- Translating scientific developments into policy and programmes through mobilization, organization and advocacy, and where necessary, litigation and other forms of direct action.

Most importantly, the community must continue to hold stakeholders – including civil society organizations themselves – to account. We should never apologise for getting our foot in the door or occupying seats at the decision-making table. But at the same time, we must remain vigilant. We cannot let participation become co-option – we have a duty to disengage as and when we are used to justify the unjustifiable.

### **Acknowledgments**

In closing, I would like to acknowledge the following people:

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I thank you.

[ENDS]