Abstract

South Africa faces among the world's highest burdens of both HIV and TB. These diseases affect not only the same populations, but often the same patient; HIV/TB co-infection has a compounding effect that creates a greater public health problem than the sum of its parts. In recognition of the need to address HIV/TB co-infection, South Africa is integrating the responses to both diseases under the National Strategic Plan for HIV, STIs and TB, 2012-2016. However, the two diseases have previously been addressed in very different ways, particularly when it comes to human rights considerations. Rather than a reconciliation of these two approaches, the NSP more closely resembles the ongoing response to HIV; while this approach may yield some benefits when applied to TB, it also risks undermining the unique characteristics of TB as well as its overall role in the co-epidemic, with potential repercussions for the effectiveness of the NSP. Through examining the historical roots of these approaches, both in South Africa and internationally, this paper explores how different factors, including the way different stakeholders have engaged with each, have influenced the development of the NSP, and what the implications are for its effective implementation. It is hoped that by focusing attention on TB, the stakeholders charged with monitoring and implementing the NSP will recognize the necessity of giving due consideration to both diseases in enacting a unified response to the co-epidemic.
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Glossary

This glossary is adapted in part from the National Strategic Plan on HIV, STIs and TB, 2012-2016, and from the UNAIDS Terminology Guidelines (Revised Version) October 2011.

ART Antiretroviral therapy.

DR-TB Drug-resistant tuberculosis.

Extrapulmonary TB TB disease in any part of the body other than the lungs.

HAART Highly active antiretroviral therapy.

IPT Isoniazid preventive therapy.

MDR-TB (Multidrug-resistant tuberculosis) A specific form of drug-resistant tuberculosis due to a bacillus resistant to at least isoniazid and rifampicin, the two most powerful anti-tuberculosis drugs.

MMC Medical male circumcision.

Nosocomial Infection/Transmission Occurring within a hospital or healthcare facility setting.

NSP National Strategic Plan.

PICT Provider-initiated counselling and testing.

MTCT Mother to child transmission (of HIV).


TAC Treatment Action Campaign.

VCT Voluntary counselling and testing.

XDR-TB (Extensively drug-resistant tuberculosis) DR-TB that, in addition to resistance to isoniazid and rifampicin, is also resistant to fluoroquinolones and at least one injectable second-line drug.
Chapter 1: Introduction

Apart from a brief phase when it seemed to epitomize “democracy triumphant,” AIDS has increasingly replaced apartheid as the one word automatically conjured up by the name “South Africa”.

HIV has been one of the defining factors in South Africa's development over the past two decades. Yet many of those who take the image of an AIDS-ravaged African country for granted would be surprised to learn that the infectious disease responsible for the most deaths in South Africa today is not HIV, but tuberculosis. The numbers tell some of the story. South Africa still has the most people living with HIV of any country in the world, an estimated 5.6 million; with less than one percent of the world's population, South Africa bears 17% of the world's HIV burden. But while HIV prevalence has stabilized over the past four years, and incidence dropped by 1/3 between 2001 and 2009, TB is still increasing; of the world's highest-burden countries, the World Health Organization (WHO) estimates that South Africa was the only one where TB incidence increased in 2010. That year, South Africa reported the third largest number of TB cases in the world, behind only the far more populous countries of India and China.

Yet the full story can't be told by comparing statistics for one disease against the other, as the two are intimately connected, not only from a medical perspective but a social one. Diseases of

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poverty, and even more so of inequality, HIV and TB affect not only the same populations, but often
the same patients; a patient presenting with TB in a South African clinic has a greater than 70% chance
of being HIV-positive\(^9\). The situation is made even worse by the rise in drug-resistant strains of
tuberculosis that are harder and more expensive to diagnose and treat, if they can be treated at all.
Against this background, progress against one disease will be impossible if the other is ignored.

Yet even as HIV/TB co-infection creates a public health crisis greater than the sum of its parts,
very different approaches have been taken to solving the two halves of the equation. This is true all
over the world; indeed, to a large extent, the approaches that have been used to combat HIV and TB in
South Africa were developed in the West, and were exported without proper consideration for whether
they were appropriate. These approaches, exported decades apart, in turn take very different stances
when it comes to the rights of the patient. HIV, viewed from the start as a unique case in public health
through the lens of HIV Exceptionalism\(^10\), sees an integral role for human rights and patient autonomy
in the response, while TB responses generally retain a more traditional biomedical viewpoint with a
more paternalistic approach toward the patient. Nevertheless, the last decade has slowly brought
recognition not only to the links between these diseases, but the necessity of linking the responses as
well. It is becoming clearer that medical advances, and from a very different perspective the resurgence
of TB, are making HIV appear less exceptional, while traditional approaches to TB are inadequate in
the face of new challenges posed by HIV co-infection and rapidly increasing drug resistance.

(SANAC) released the National Strategic Plan on HIV, STIs\(^11\) and TB, 2012-2016 (“NSP”)\(^12\).

\(^9\) Lawn, Stephen; Anna Fraenzel, Katharina Kranzer, Judy Caldwell, Linda-Gail Bekker, Robin Wood, “Provider-initiated
HIV testing increases access of patients with HIV-associated tuberculosis to antiretroviral treatment” South African

\(^10\) Both AIDS Exceptionalism and HIV Exceptionalism are used in the literature, and are synonymous.

\(^11\) Despite the title of the NSP, STIs are almost completely absent from the document. While this poses serious concerns
when trying to apply the NSP in the STI response, this paper addresses only HIV and TB.

\(^12\) South African National AIDS Council, National Strategic Plan on HIV, STIs and TB, 2012-2016 (“NSP”). Online:
crucial advance of the NSP is that for the first time it adopts a unified approach to HIV and TB, recognizing that, particularly in South Africa, the two diseases cannot be addressed separately. Although it marks a considerable step forward, however, the consolidation of the approaches has largely involved drawing TB into the existing HIV response, rather than taking steps to reconcile two approaches that advocate treating the same patient in very different ways in a manner that retains the most effective aspects of each. The resultant plan both underemphasizes TB-specific interventions and, conversely, undermines the potential benefits of broadening the rights-based HIV approach to include TB.

The purpose of this paper is not to exhaustively analyze the effectiveness of the proposed interventions so much as to examine the context in which an emphasis on HIV, and its accompanying discourse, have led to imbalanced approach to the HIV/TB co-epidemic. It begins by setting out the South African context and the characteristics of the co-epidemic, followed by an examination of the historical development of the approaches to each disease both internationally and in South Africa, before returning to address how these factors have influenced the NSP and the implications for its effective implementation. By highlighting these issues, it is hoped that the stakeholders charged with monitoring and implementing the NSP will recognize the necessity of addressing the co-epidemic as a whole.

**Chapter 2: The NSP in Context**

**Two Diseases, Two Eras**
The Human Immunodeficiency Virus (HIV) which, if left untreated, eventually leads to Acquired Immunodeficiency Syndrome (AIDS) and not long thereafter death, is a very new disease in human terms. The condition that would come to be known as AIDS was first described in 1981 in the United States\(^{13}\), initially associated with the homosexual community, it was soon identified in other

populations. The term AIDS was defined by the Centre for Disease Control (CDC) in September 1982\textsuperscript{14}, while the virus itself, HIV, was first identified in 1983. The response to the disease was shaped by the fact it was first identified in a Western country in a social climate favourable to making human rights a crucial component of the response; as awareness of HIV spread around the world, so too did the West's emphasis on human rights in the response.

By contrast, mankind has lived with tuberculosis for thousands of years; it has been identified in Egyptian mummies\textsuperscript{15} and may in fact be far older\textsuperscript{16}. Although historically one of the great scourges of mankind, effective treatment has been available for over half a century. Thus, while historically it was influential in the creation of Western public health measures just as it inspired, and claimed, some of the Western world's leading cultural figures\textsuperscript{17}, today these countries largely consider it a disease of the past. Since the West plays the dominant role in both funding and policy for global health, this resulted in TB being nudged from the spotlight before HIV brought human rights onto the public health stage, even while it remained a serious problem in much of the rest of the world. Thus, HIV, arguably the highest profile health issue of the past 30 years, has been the focus of much of the attention, investment and innovation in public health over this period, while TB has maintained a lower profile in all three respects, even as drug resistance threatens to revitalize an old threat. Their perceived importance to global health is demonstrated by their respective roles within Millennium Development Goal 6: Combat HIV/AIDS, Malaria and Other Diseases, where HIV gets top billing while TB receives only a bit part within the sub-goals as one of the “other diseases”\textsuperscript{18}. Today, however, the intersection of one of


\textsuperscript{17} Chalke, H.D. “The Impact of Tuberculosis on History, Literature and Art” \textit{Medical History} Oct.1962 Vol.6 Iss.4 pp.301-318.

mankind's oldest diseases with one of its newest to create the co-epidemic facing South Africa necessitates a re-evaluation of how they are approached.

**South Africa: the Setting for Integration**

Under ideal circumstances, tuberculosis is a curable disease while HIV is a chronic, manageable one; for many South Africans, however, circumstances are far from ideal. As with the two diseases in question, the environment in which the NSP is to be deployed influences how it develops and what its effects will be. This South African environment is itself a complex and at times contradictory one. When addressing the causes of the HIV/TB co-epidemic, the question arises whether it is a combination of a virus and a bacterium, of social ills and economic inequalities, or all of the above. Recognizing the importance of both biomedical and socioeconomic factors is another triumph of the NSP.

Identifying the biomedical causes of HIV and TB is crucial, and yet has proven controversial in South Africa, particularly in the case of HIV. These controversies have complicated the response, and the interactions between stakeholders. Nor are HIV and TB the only health challenges facing South Africa; today, the government acknowledges that the national health system faces “a myriad of challenges, among these being the worsening quadruple burden of disease (HIV/TB, maternal and child death, non-communicable diseases, violence and injuries) and shortage of key human resources.” HIV and TB thus must be considered within the context of the overall burden of disease and the burden on the health system itself.

The broader social ills implicated in the co-infection epidemic have proven similarly complex. South Africa is the largest economic power in Africa; it is now the “S” in the BRICS group of emerging economies. With tremendous resources at its disposal, it is one of the only African countries that fully

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funds its own TB program\textsuperscript{20}, while also funding close to three quarters of its HIV program\textsuperscript{21}. This is far from the view of the penniless, hopeless African state used by rock stars to solicit charitable donations.

At the same time, in 2008 South Africa surpassed Brazil to become the most unequal society in the world\textsuperscript{22}; while given a formidable start by the legacy of apartheid, these new heights of inequality cannot be blamed on the past alone. Similarly, if an intervention remains inadequate in the first place, it does not matter that it is fully funded. Education level, unemployment, household income, and economic and social inequality have all been linked to both HIV and TB\textsuperscript{23} in South Africa; these inequalities affect both who receives treatment, and who gets ill in the first place.

A similar balancing act occurs when charting out the human rights landscape in which the NSP operates. The division of supposedly universal human rights into categories begins at the highest international level, as demonstrated by the fact that the Universal Declaration of Human Rights (UDHR) only takes legal effect once split into two separate covenants\textsuperscript{24}. As will be seen throughout this paper, civil and political rights have been weighed against social and economic rights, while the rights of the individual have been stacked up against the rights of the broader community. On the surface, the NSP adopts an expansive approach to rights, stating:

South Africa’s response to HIV, STIs and TB recognizes the centrality of constitutional values and human rights. This is based on the understanding that public interest is best served when the rights of those living with HIV and/or TB – or are at risk of infection – are respected, protected and promoted. Not only is this globally accepted public policy, it is also in line with the rights entrenched in Chapter 2 of the South African Constitution and the obligations these impose on the state regarding their progressive realization.


\textsuperscript{24} The International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR). The historical and political motivations behind this separation are fascinating, but beyond the scope of this paper.
Among others, these include the rights to equality, dignity, life, freedom and security of the person and privacy. The NSP takes as a starting point the constitutional recognition that access to health care and other social services – which includes reproductive health care – is itself a right enshrined in the constitution\textsuperscript{25}.

Thus, human rights are an explicit and central consideration in the NSP. In this context, the Bill of Rights under the South African Constitution is one of the most progressive in the world. When it came into force in 1997, it was, for instance, the first in the world\textsuperscript{26} to explicitly recognize sexual orientation as grounds for equality\textsuperscript{27}. It also goes beyond the inclusion of civil and political rights, the so-called negative rights with which the state is not to interfere, to include a range of positive economic, social and cultural rights which the state must actively promote. The most crucial of these in the context of the HIV/TB co-epidemic is the following, alluded to in the NSP above:

27. Health care, food, water and social security
   1. Everyone has the right to have access to
      a. health care services, including reproductive health care;
      b. sufficient food and water; and
      c. social security, including, if they are unable to support themselves and their dependants, appropriate social assistance.
   2. The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realization of each of these rights.
   3. No one may be refused emergency medical treatment\textsuperscript{28}.

At the same time, the laws on the books do not always reflect justice on the streets. Hate crimes against the gay community continue, while many South Africans still do not receive adequate healthcare. And as will be discussed later, the government, tasked with upholding the Constitution, has itself sometimes violated it at the expense of the ill and the underprivileged; in such cases, the Constitution has been turned upon the government to enforce these rights. These conflicts are not unique to South Africa; disputes over the proper prioritization of rights are a common thread throughout this paper.

\textsuperscript{25} NSP, p.53.
\textsuperscript{26} Altman, Dennis “HIV, Homophobia and Human Rights” Health and Human Rights 1998 Vol. 2 No.4 pp.15-22.
\textsuperscript{27} Constitution of the Republic of South Africa, 1996, Chapter 2 – Bill of Rights, s.9(3).
\textsuperscript{28} Constitution of the Republic of South Africa, 1996, Chapter 2 – Bill of Rights s.27(2)
This brings the discussion to another crucial contextual element for the NSP, the stakeholders. Their importance becomes even clearer with the realization that, rather than a detailed blueprint for the response to HIV and TB, the NSP is “a multi-sectoral, overarching guide that will inform national, provincial, municipal and community-level stakeholders on the strategic directions to be considered when developing implementation plans [emphasis in original].” Consequently, multiple parties have the potential to exert considerable influence on the extent to which these strategic directions are followed. The parties to the consultation and drafting process for the NSP give some idea of the range of stakeholders involved; these include not only high-ranking representatives of the South African government, but medical experts, international organizations and South African civil society. All these stakeholders impacted what went into the NSP, and in turn will impact what comes out of it.

The most crucial contextual element, however, and the one that forms the focus of this paper, is that HIV and TB boast different historical trajectories, which exert effects both from within South Africa and abroad. The primary historical consequence is that HIV has taken centre stage, pushing TB out into the wings even as efforts are made to give them both a starring role in the NSP. This is aptly illustrated by the fact the new NSP is under the jurisdiction of the South African National AIDS Council (SANAC), a body created with an explicit mandate to address HIV. TB, formerly a responsibility of the Department of Health, has here been drawn under the SANAC umbrella with little fanfare. Thus, although ostensibly heir to both the HIV & AIDS and STI Strategic Plan for South Africa, 2007-2011 (“NSP-HIV”) and the Tuberculosis Strategic Plan for South Africa, 2007-2011 (“NSP-TB”), the new NSP draws heavily from the former while largely neglecting the latter. As a result, the shift in the approach to TB as a result of the integrated NSP is far greater, but occurs without discussion. This is in part because many of the stakeholders tasked with drafting the NSP have a much

29 NSP, p.19.
greater history with HIV than TB. As will be explored later, civil society's role in particular was
galvanized by HIV, and only recently has much attention been directed towards TB. This is true of the
Treatment Action Campaign (TAC), a landmark group in the response to HIV in South Africa that has
itself only recently begun to address TB, and which was among the few stakeholders to provide
extensive TB-focused feedback during the NSP drafting process. This HIV-centric approach drew
TAC's attention when reviewing the first draft of the NSP:

Insufficient emphasis is placed on TB throughout the current draft, particularly in the
main text. Although paid lip-service throughout the document, it often appears that TB
has been simply inserted into an HIV document. For instance, where examples of
interventions are provided, they focus primarily or entirely on HIV. While in some cases
the same intervention will be appropriate for both conditions, TB also requires specific
action. Ensuring that TB-related examples of interventions are included in all instances
would both give TB the prominence it deserves and emphasize the integration of TB and
HIV.\(^{32}\)

Certainly, this is not the first case where HIV policy materials have quickly been retrofit for use with
TB in South Africa. For instance, a fact sheet on TB discrimination published by South Africa's
Department of Justice and Constitutional Development tellingly includes a reference section consisting
of eight documents on HIV and discrimination, and none on TB.\(^{33}\) Yet while TB's role in the NSP has
expanded throughout the drafting process, it is still treated as the junior partner in the co-epidemic. Its
role in the NSP ultimately comes across as an inclusion most parties clearly thought was a good idea,
but for reasons far fewer were comfortable articulating.

The awkwardness around TB's inclusion extends to basic principles such as evincing a clear,
unambiguous understanding of what infection means in the context of TB and how it differs from HIV.
This confusion about what would seem to be a fundamental underpinning of a joint response
nevertheless inadvertently highlights a parallel between HIV and TB that is generally overlooked:

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people can remain healthy for long periods after infection. This has long been widely recognized for HIV; indeed, the ability for those infected to live healthy lives for years before falling sick has been one of the underlying motivations for a rights-based approach to HIV. In contrast, it is still a matter of confusion in terms of general knowledge surrounding TB, even though TB infects far more people. It is generally estimated that roughly 1/3 of the world's population is infected with *Mycobacterium tuberculosis*; in South Africa, that figure is closer to 80%. Under normal circumstances, only the minority of those infected will ever progress to active tuberculosis; for roughly 90% of these people, the infection will remain latent, never causing any illness or spreading infection to others. Yet the initial drafts of the NSP use the term infection to refer to both active infection – TB disease – and latent infection. Only in the final draft is the difference between TB infection and disease clarified. This is no mere technicality; rather, it is of great importance in the context of the co-epidemic, as latent TB has more serious implications in the presence of HIV than it would on its own. Even with this clarification, however, a goal of zero new infections for HIV has significantly different implications than for TB. For the former, infection will eventually lead to illness in virtually all patients who do not receive treatment, and virtually all those infected will be capable of transmitting the virus even while seemingly healthy. For the latter, the majority will suffer no ill effects and never pose a risk to others, while the minority who become ill can be highly infectious through means of transmission that are much harder to fully address. Nevertheless, the stated long and short term goals are the same for both, once again illustrating that HIV is the driver of policy in the NSP.

**Coordination of Co-infection: Reasons for Integration**

It is perhaps for this reason that although the introduction to the NSP states that the development of a single integrated strategy is “due primarily to the high HIV and TB co-infection rate,” the motivations

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34 NSP, p.13.
35 Clarification of this issue was a prominent point in TAC's initial submission.
36 NSP, p.5.
behind a joint approach are never really explored. Without further explanation, and given that they appear in the same people, often at the same time, the logical inference would be that integration of HIV and TB responses is motivated by efficiency. If the same person needs to access both services, it is simplest if they can do so in the same place, talking to the same healthcare worker who is looking at a single chart. The benefits of a simplified model for the patient seem clear, while combining services also makes sense from the perspective of an overtaxed and underfunded health system.

The evidence supports this view. A 2004 study examining the feasibility of integrating HIV and TB care in South Africa noted that, beyond erratic referral of patients between the two, the services functioned independently, often duplicating services unnecessarily. Among the laundry list of observations were: “Separate patient folders are kept in each service, without exchange between caregivers; the clinicians in the different services are unaware of other treatments; and dually infected patients are seen at two services and by different health staff, at different times and places.” The authors of the study noted that integration of care would result in optimal use of available human and financial resources with benefits for both the patient and the health system. More recent studies have reached similar conclusions.

Efficiency is certainly one aim, and one benefit, of an integrated NSP. However, to stop the analysis here would suggest integration is merely a matter of cost-cutting and streamlining made possible by the convenient convergence of two diseases in one patient, allowing for substantial efficiency gains by creating a one-stop-shop where all that patient's needs may be met. To implement the NSP based solely this premise would prove sorely inadequate to the job at hand. The reality is that the two epidemics are not fortuitously running in parallel, but tragically intertwined; the burden of the

38 Ibid.
HIV/TB co-epidemic is not merely the sum total of the two separate epidemics together, but the result of their interaction. At the same time, each possesses unique characteristics that an intervention based solely on efficiency risks glossing over. Consequently, it is necessary to delve into the mechanics of the co-epidemic to determine why a joint approach is so necessary.

**HIV and TB: A Deadly Combination**

From a biomedical perspective, HIV is the greatest risk factor for tuberculosis ever known. This occurs because HIV leads to a decline in the immune system, decreasing the ability to prevent the replication and dissemination of *M. tuberculosis*. The risk is detectable as early as seroconversion and increases in parallel with increasing immune suppression throughout the course of HIV disease. For someone co-infected with both HIV and TB, the chance of developing active TB is no longer one in ten over a lifetime, but one in ten every year. At the same time, TB is the most common cause of death worldwide in people who are HIV-positive. Indeed, TB is the most common presenting opportunistic infection among HIV-infected patients, although classifying TB as a mere opportunistic infection downplays the threat it poses on its own. The relationship between the two infections is not unidirectional; there is evidence that the patient's immune response to tuberculosis actually increases viral replication of HIV.

Given the high prevalence of both HIV and TB infection in South Africa, the chance of the two

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overlapping is high. As a result, the epidemics feed off of each other despite the fact that a co-infected patient is likely to infect fewer people with TB than one with TB alone\textsuperscript{46}. This is because, as discussed further later on, co-infected patients are less likely to exhibit the typical symptoms of TB and as a result are less infectious. Similarly, the duration of infectiousness may be shorter because progression of disease is more rapid in co-infected patients\textsuperscript{47}. However, the co-mingling of HIV and TB nevertheless escalates the epidemic, as described here:

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Before the advent of HIV, 10% of those infected with tuberculosis would be expected to progress to active tuberculosis disease over their lifetime, of whom about one-half would have infectious, usually sputum smear positive, disease. It follows that if one infectious case of tuberculosis successfully infected 20 other people, one was likely to develop smear positive or infectious tuberculosis and the disease would be maintained at a stable level in the community. When HIV is added into the equation the same infectious individual will still infect 20 others but some of these will be HIV infected. If we consider a scenario where HIV prevalence is 10% (a situation exceeded in some of the worst affected countries) then two of the infected contacts will be HIV positive. These HIV-positive individuals, once infected with tuberculosis, will be expected to progress to active disease more rapidly and more cases of active disease will occur in addition to the cases from the 18 HIV negative individuals. Even allowing for a greater proportion of non-infectious (smear negative or extrapulmonary) tuberculosis this results in a net reproduction rate greater than 1 and an expanding epidemic\textsuperscript{48}.
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The interplay of HIV and TB also complicates the response to the diseases. This extends to assessing cause of death; while in 2008, TB was recorded as the leading cause of death in South Africa (12.6% of deaths), and HIV was seventh (2.5%)\textsuperscript{49}, difficulties in assessing the cause of death in cases of co-infection, not only HIV/TB but with other diseases, make it difficult to assess the accuracy of these figures and the relative contributions of these conditions to mortality. In the case of HIV, attribution of


\textsuperscript{48} Godfrey-Faussett, Peter & Ayles, Helen. “Can we control tuberculosis in high HIV prevalence settings?” Tuberculosis 2003 Vol.83, pp.68–76.

death to other conditions may also be affected by the stigma around HIV, an issue discussed later.

However, these difficulties begin far earlier in the response. Historically, testing for HIV and TB have not been well-coordinated, with patients with one diagnosis frequently not tested for the other despite the high level of co-infection. As a result, efforts to encourage testing of TB patients for HIV and vice versa have increased in South Africa under the NSP-TB and NSP-HIV, and form an important component of the NSP. While this co-ordination of testing is important, less attention has been given to the fact that co-infection can be difficult to assess because one infection makes the other harder to diagnose. A range of other opportunistic infections that occur during late-stage HIV disease may resemble TB, and vice versa. Thus, similarity between symptoms may lead to a misdiagnosis, or a situation where the confirmation of one disease leads to the other being overlooked.

In the case of HIV, an HIV test is the usual method of diagnosis, and when performed, the results are unaffected by co-infection. However, given resource shortages, the first measure in TB diagnosis in South Africa remains symptom screening; specific tests for TB are generally performed only after a positive screening. This is the case in the national testing campaign currently underway\textsuperscript{50}. While screening can be effective under normal circumstances when diagnosing TB, it is made more difficult in the case of co-infection by the fact that TB manifests itself differently in patients with HIV. The difficulties created by these different manifestations extend to more specific diagnostic tests as well. Chief among these differences is that many co-infected patients do not show any lung infection at all. The first study linking AIDS to extrapulmonary TB was presented in May 1984\textsuperscript{51}; since then, the high level of extrapulmonary TB in Sub-Saharan Africa has been recognized as greatly complicating TB detection and control\textsuperscript{52}.

\textsuperscript{52} Perkins, Mark D. & Cunningham, Jane “Facing the Crisis: Improving the Diagnosis of Tuberculosis in the HIV Era” The
The usual diagnostic test used in South Africa, which has the advantage of being inexpensive and relatively quick, is smear microscopy. It is effective for diagnosing the “typical” TB case, smear-positive pulmonary TB. However, patients with HIV are considerably less likely to present a “typical” case; the WHO reports that in 2010, only 45% of TB cases in South Africa were smear positive\(^{53}\). A more reliable test is a laboratory culture of a patient's sputum; this test already has the disadvantage of being slow (often over 6 weeks). Here too, HIV/TB co-infection may be more difficult to diagnose. Even where co-infected patients do have pulmonary TB, patients weakened by later-stage HIV disease, as well as children, are less likely to be able to cough hard enough to produce a sufficient sputum sample. A tool called a nebulizer can be used to create an appropriate sample; however nebulizers are not available in all facilities in South Africa\(^{54}\). Non-pulmonary tests may be of little help; the Mantoux test, a commonly used tuberculin skin test, is also less accurate in HIV-positive patients\(^{55}\) as well as in people who have received the Bacille Calmette-Guérin (BCG) tuberculosis vaccine\(^{56}\), as many in South Africa have.

Thus, difficulties in diagnosis have a disproportionate effect on TB, a factor which needs to be considered in dual-testing initiatives. Furthermore, these difficulties in diagnosis mean that South Africa may be under-reporting TB, particularly in cases of co-infection, as well as for certain groups such as children that are harder to diagnose. As a result, it is both more difficult to provide the individual patient with the treatment they need, and harder to assess the scope of the problem in order to plan a proper response at the population level.

A further reason that diagnosis of co-infection is crucial is that measures are available to prevent


\(^{54}\) TAC's submission that nebulizers and other diagnostic tools be specifically identified as priorities was removed from the final draft of the NSP.


illness if diagnosed early enough. For HIV-positive patients with latent tuberculosis, or who are not infected but are at a high risk of TB infection, isoniazid preventative therapy (IPT) is effective in preventing active tuberculosis. IPT has also recently been scaled up in South Africa, increasing by more than five-fold in one year, from 23,583 in 2009 to 124,049 in 2010\textsuperscript{57}. However, to be effective, active TB must be ruled out before receiving IPT; to do otherwise can complicate TB treatment later by increasing the risk of drug resistance. Similarly, earlier antiretroviral therapy (ART) in co-infected patients is effective in reducing not only the advancement of HIV but the development of active TB. Thus, immediate ART in cases of co-infection is the standard currently recommended by the WHO, and is now the standard advocated in the NSP\textsuperscript{58}. The positive effects of ART treatment are long-lasting; even after five years, incidence of TB continues to decrease in patients on treatment\textsuperscript{59}. Furthermore, there are decided advantages to early initiation of HIV treatment; patients treated only after they were already severely immunodeficient retained an increased risk of TB while on ART, perhaps reflecting a limited capacity for immune restoration\textsuperscript{60}. The importance of providing treatment early, rather than after patients are already sick, further emphasizes the need to ensure proper diagnosis of both diseases.

The difficulties posed by co-infection do not stop there. Even once patients have been diagnosed, treatment options are affected by co-infection. A commonality of HIV and TB is that both are highly prone to developing drug resistance; thus, effective treatment of each must consist of a multi-drug cocktail. However, this means that a co-infected patient is ingesting a large number of powerful medications. Treating co-infection poses three main risks from a medical perspective\textsuperscript{61}. One is


\textsuperscript{58} NSP, Intervention 3.1.7, p.49.


\textsuperscript{60} Ibid.

that certain TB drugs can interfere with antiretrovirals, making them less effective; this can be avoided by using alternative drugs, although these alternatives may be more expensive. A second is that treatment for both diseases can be toxic, resulting in unpleasant side effects; this can increase the risk of non-adherence, particularly given that the more drugs the patient is taking, the more difficult it is to determine which drug or combination of drugs is causing the problem. The third is a phenomenon known as “immune reconstitution inflammatory syndrome” (IRIS); broadly speaking, this results when the immune system, depressed by HIV, begins to recover, but then responds to the tuberculosis infection with an overwhelming inflammatory response that makes the symptoms of infection worse, and can be fatal. However, in most cases the potential benefits of treatment outweigh the risk of IRIS. Similarly, early ART helps to decrease the possibility of virus mutation and drug resistance.

Nevertheless, these risks mean that patients require monitoring for ill-effects, placing an additional burden on health resources. Although the need to monitor side-effects is mentioned in the NSP, the additional burden of co-infection is not addressed. In the case of drug-resistant TB, which is even more difficult to diagnose, and for which a larger number of drugs must be taken over a longer period and with greater involvement of health professionals, the issues above are compounded further.

As the above discussion illustrates, co-infection complicates the response to both HIV and TB at every step of a medical intervention. While understandably the NSP is meant as a policy document, not a medical textbook, the fact that it contains less than one page on the epidemiology of both diseases, with virtually no mention of co-infection, means that the subsequent interventions lack this context. At the same time, to be effective, the NSP must also account for differences between the two diseases, and

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64 NSP, p.50.
instances where they do not act in tandem. The most immediate example of such a difference is the mode of transmission. HIV is transmitted through the transfer of blood and other bodily fluids; in South Africa, the primary mode of transmission is heterosexual intercourse. Not only is this a remarkably inefficient method of transmission biologically, it also places inherent social limitations on transmission; it is the result of an act requiring the participation, hopefully consensual\(^{66}\), of two people, an act that usually takes place only in certain circumstances. By comparison, tuberculosis is readily transmitted in enclosed spaces, such as shared living or working space. While not extremely likely, a night at the cinema or riding a crowded bus could lead to infection. It also makes South Africa's epidemic everyone's concern; in today's globalized world, not only can TB travel from place to place, but it can infect passengers in the airplane \(^{67}\).

These differing modes of transmission have immediate implications for the integration of HIV and TB services in a healthcare setting. As access to integrated treatment expands, venues providing these services become, by design, gathering places for immunodeficient patients seeking those services. Putting an infectious TB patient in a room full of immunodeficient people is a recipe for the spread of disease\(^{68}\). Thus, infection control programs are crucial. This includes not only well-ventilated facilities, but prompt identification of suspected infectious TB patients with triage into diagnosis and treatment, as well as separation from those they might infect.

Concerns about the extent of infection control measures for TB in early drafts of the NSP were largely addressed, and they are prioritized in the final draft. However, the issue of nosocomial transmission of tuberculosis also illustrates an area where human rights considerations have been based

\(^{66}\) Though beyond the scope of this paper, the levels of both gender inequality and sexual violence remain high in South Africa, and are the focus of a considerable number of HIV interventions in the NSP.


largely on conceptions developed around HIV with insufficient thought given towards TB. Where health systems are already strained, a loss of healthcare workers for any reason is especially serious. Given their importance to the response, as well as the personal risks they face in caring for others, healthcare workers require special consideration; while this has long been recognized for HIV, it needs to be prioritized for the far more infectious TB, particularly given both the increasing risk of drug-resistant TB, and the dual risk faced by HIV-positive healthcare workers. Healthcare workers have faced barriers in accessing compensation for TB; similarly unrecognized is the fact that healthcare workers may also face threats, including physical violence, from involuntarily isolated TB patients.

Submissions made during the consultation process to explicitly highlight the rights of healthcare workers working with TB in the NSP, including a commitment to ensure they were supplied with adequate supplies of personal protective gear such as respirators, were not integrated into the final draft. Their omission once again suggests that insufficient attention is being given to the unique circumstance of TB.

Social Interaction: Social Impacts of Co-Infection

Thus far, this paper has focused largely on issues surrounding the diagnosis and treatment of the individual. An infectious disease, however, requires a social context in which to thrive, and here too the co-epidemic inflicts broader social scars than HIV and TB alone. As mentioned earlier, both diseases are more likely to affect certain societal groups, and the double burden of disease would take a heavy toll on these communities even if the two were not interlinked. At the same time, co-infection has even shifted the profile of TB patients towards the demographic most affected by HIV. The highest increases in the TB notification rate have correlated with the age group with the highest HIV infection rate, those

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20-39 years old\textsuperscript{71}. Within this group there is evidence that, as with HIV, the women bearing the highest burden are generally a decade younger than the men\textsuperscript{72}. Thus, unlike in industrialized nations where TB is more likely to afflict the elderly, in South Africa it, like HIV, is most likely to affect adults in the prime of their economically productive lives. Co-infection also has a disproportionate impact on women; not only are women more likely to be co-infected, but they are also harder to diagnose, as women are less likely to produce positive sputum samples and more likely to have extra-pulmonary TB\textsuperscript{73}. South African studies show pregnant women living with HIV face particularly serious risks from co-infection with TB\textsuperscript{74}. Thus, co-infection heightens the economic and social impacts associated with HIV, attacking the most economically active segment of society while exacerbating differential effects based on gender.

Nevertheless, TB is again overshadowed, even though it poses particular risks to certain communities separate from its links to HIV. While the NSP does identify certain groups as priorities for intervention due to a particularly high risk of TB infection or progression to active TB disease, these communities are subject to considerably less discussion than those at risk for HIV; while each key population at risk of HIV is described in detail\textsuperscript{75}, those for TB are merely listed with no further discussion\textsuperscript{76}. In fact, although it is used in the main text in the context of both diseases, the term “Key Populations” is defined in the glossary only with regard to HIV\textsuperscript{77}. This betrays a much higher level of comfort with HIV risk factors than TB. For instance, submissions were made at all stages of


\textsuperscript{75} NSP, p.26.

\textsuperscript{76} NSP, p.27.

\textsuperscript{77} NSP, p.6.
consultation, by TAC and by others, to explicitly expand reference to miners as an at-risk group to include both current and former miners, as the increased risk of TB in miners, due in part to high levels of work-related silicosis, continues even after the miner is no longer employed as such. Nevertheless, even though both miners and silicosis are mentioned in the NSP, the connection to ex-miners is bizarrely noted only in a single footnote in the context of migrant labour\textsuperscript{78}. This risks future interventions overlooking this important group, particularly given that the industry is no longer at its peak levels of active employment. And while many broad social and economic factors linked to HIV or to both TB and HIV are mentioned, other TB-specific risk factors, such as indoor air pollution from sources such as cooking fires, are omitted entirely.

This lack of attention to TB integration is also visible in the even more explicitly social context of stigma and discrimination. Just as HIV and TB compound each other's effects in a co-infected patient, so too do the stigmas build upon one another. Although TB stigma had historically decreased in South Africa thanks to the availability of a cure, it re-emerged when it became a marker for AIDS\textsuperscript{79}. It has also been suggested that in some communities it is now thought that TB inevitably leads to HIV\textsuperscript{80}. Indeed, it has been argued that “TB stigma can no longer be thought of, or addressed, separately from HIV stigma; in effect a new disease stigma has unfolded, namely TB-HIV stigma\textsuperscript{81}.” The consequences of such joint stigma will almost certainly affect other interventions. For instance, the presence of health workers making home visits for one disease can raise awareness of the presence of the other in a household, potentially leading to stigmatization of the occupants\textsuperscript{82}. At the same time, although HIV stigma has been the subject of considerable study and plays a central role in many HIV

\textsuperscript{78} NSP, p.35.
programs, TB stigma has been largely ignored by the academic community, let alone included in global TB strategies. UNAIDS recently noted that “a rights-based approach to HIV-related TB... has largely been neglected.” One study examining this issue concluded that the “failure of the TB world to address stigma is a reflection perhaps of how implicit biomedical power and control is in TB history, discourse and practice, and consequently how TB research and practice often fails to address the complexities of peoples' lives,” issues that will be explored further later on. This being the case, the emphasis on reducing stigma for both HIV and TB in the NSP should be welcomed. At the same time, it overlooks the fact that, as a result of worldwide neglect of this issue, far fewer tools exist to even measure TB stigma.

Furthermore, it overlooks the fact that different interventions will be required to change attitudes and behaviours. For instance, the acts associated with TB transmission are not private acts, and therefore do not carry the same social baggage; while the risk of transmission is greater, the stigma attached to the mode of transmission is paradoxically smaller. There are few barriers anywhere in the world to talking about coughing, while sex remains considerably more taboo, and in some cases illegal. At the same time, while it may be possible for people living together in a cramped room to change their behaviour to refrain from sex if one is infected with HIV, if the other is diagnosed with TB, it is difficult to alter their behaviour to stop breathing. Consequently, joint interventions aimed at stigma reduction and behavioural change will need to address considerably different issues. It is also telling that in the very last draft circulated before publication, a key NSP objective relating to stigma still only mentioned HIV; even if an unintentional typo, it illustrates TB being overlooked once more in the NSP.

86 NSP, p.12.
In fact, even though on first glance the NSP appears to prioritize human rights for both diseases, closer inspection reveals that this approach remains focused on HIV. A section of the NSP outlining HIV and TB as development challenges makes the following statement about HIV: “Almost from the beginning, HIV has also been understood as a human rights issue – the denial of human rights increases the risk of HIV infection, and HIV infection increases the risk of human rights violations. It is for this reason that a human rights approach has been a core principle of the HIV response.” It does not make any similar claims for TB, a disease that has less commonly been understood as a human rights issue but could benefit from such an analysis. Taken together, these interactions, both biological and social, demonstrate that co-infection is a bigger problem than merely the summation of the independent burdens of the two diseases. This discussion also demonstrates that this fact is never fully explored in the NSP. In their analysis of the final product, TAC reached the following conclusion:

[T]he NSP ultimately never truly drives home the most important reason for addressing both diseases under the same strategy: that HIV/TB co-infection poses a risk greater than the sum of its parts, as the two diseases reinforce each other, making the patient with one more susceptible to the other while making treatment and diagnosis more difficult. Thus, integration of services for education, diagnosis and treatment of HIV and TB is crucial not because it is convenient or cost-effective to address the conditions at the same time, but because it is no longer possible in South Africa to tackle one without also tackling the other.

It is thus demonstrated that the NSP underemphasizes TB, even where on the surface it appears well-represented. This in turn could decrease the efficacy of TB interventions, and by extension responses to the co-epidemic, under the NSP. To understand why TB is under-represented, particularly from a human rights perspective, it is necessary to look at the history of these diseases both in South Africa and the West.

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88 NSP p.30.
Chapter 3: How Exceptionalism Became Exceptional

The Rise and Fall of TB

Certainly, TB has not always been a secondary consideration. Its former status in the world of public health is captured in a piece written a few years prior to the emergence of HIV, which describes TB as “a model disease”, stating: “It is trite to say that rarely, if ever, has a disease played such a role in the history of humanity and of clinical, experimental and social medicine.” Indeed, tuberculosis laid the foundations for much of today's field of public health as we know it. It has been a key model for prevention, therapy, and epidemiology. And, as with HIV later on, most of the policy and technological innovations around TB originated in the West, even as the disease exacted a high toll elsewhere. These key innovations are, in the history of the disease, relatively new developments. Tuberculosis itself was recognized by the medical community far before they were able to take effective steps against it. It was known in antiquity by the great physicians of the time, but prognosis was not good:

Twenty-five hundred years ago Hippocrates described it as the most widespread disease of his time—and, he claimed, a disease that was almost always fatal. At the height of the Roman Empire his successor Galen saw treatment of the disease to be so often useless that he allegedly warned colleagues against visiting patients in late stages of the disease, because their inevitable death might damage the reputation of the physician.

Over sixteen centuries later, little progress had been made. Indeed, the urbanization and industrialization of Europe fostered the disease by placing people in cramped, often unhealthy, living conditions; so strong was the connection that TB was seen by many as an inevitable consequence of industrialization. Even by the turn of the 20th Century, tuberculosis remained a major killer in the West, causing, for example, close to a third of deaths in the UK. It was only in the last 150 years that a

public health response began to unfold. In the mid 19th Century, Hermann Brehmer pioneered the use of the sanitarium, one of the earliest health measures that was pioneered by TB and adopted for other conditions. The practical effects of the sanitarium have been debated, although they did have the benefit of sequestering infectious patients away from the general population\textsuperscript{94}. The actual infective agent was not discovered until 1882; Robert Koch would win a Nobel Prize for his work\textsuperscript{95}. An early model for international solidarity against disease soon followed with the first of a series of international meetings on TB in Paris in 1888\textsuperscript{96}. Before the turn of the century, diagnosis incorporated then-cutting edge technology such as the x-ray, while 1904 marked the founding of the National Association for the Study and Prevention of Tuberculosis, later to become the American Lung Association, the oldest voluntary health organization in the United States\textsuperscript{97}. The BCG vaccine, while still of uncertain efficacy, offered some protection to children from the 1920s onward.

TB in the West declined throughout the early 20th Century\textsuperscript{98}. However, there are those who question whether this decline can be attributed to public health measures. Thomas McKeown concluded that public health played a negligible role in the historical decrease in disease mortality, including from tuberculosis, during this period, instead emphasizing that increased standards of living, including better nutrition, were the deciding factors\textsuperscript{99}. His dismissal of advances in public health as a contributing factor has been largely discredited\textsuperscript{100}, including in the context of TB\textsuperscript{101}, but his broader

\textsuperscript{101} Wilson, Leonard G. “Commentary: Medicine, population, and tuberculosis International Journal of Epidemiology 2005
principles relating to the importance of wider social and economic change remain highly relevant, illustrating that the best way to remove a disease of poverty from a population is to remove that population from poverty. Indeed, the link between poverty and TB had been recognized by the medical profession for some time; Sir William Osler, sometimes considered the Father of Modern Medicine, described TB as “a social disease with medical aspects.”

It was not until the middle of the 20th Century that the battle with tuberculosis, and the conflict between socioeconomic health determinants and biomedical ones, ended with the seemingly decisive triumph of medical science. The turning point came in the 1940s with the discovery of the first drugs effective against TB, an achievement worth of another Nobel Prize. Prior to such treatment, close to half of all patients died within five years; with treatment, most patients could be cured. As more drugs were discovered, it was soon possible to close sanitoria, and treat patients entirely on an outpatient basis. A flurry of innovations followed, with implications not only for TB but for the field of public health, including the world's first randomized curative trial, and both the recognition of drug resistance and of combination therapy as a means to combat it. TB was also the first context in which health economics and population impact of disease were studied. Tools were developed so rapidly, and proved so effective, that by the 1960s, the WHO was targeting the complete elimination of TB worldwide. Yet by the time HIV appeared, TB was no longer high on the public health agenda. Why did

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such lofty ambitions and the promise of such seemingly powerful tools fade away?

This decline between the peak of TB’s prominence and the emergence of HIV can be traced in the three stages in the WHO’s approach to TB between 1945 and 1980, identified by Amrith:

The first stage was the worldwide preventive campaign of the 1950s, based on mass BCG vaccination with BCG, ‘case finding’, and data collection. The second stage, beginning in the late 1950s, involved the trial and subsequent implementation of a strategy of treating tuberculosis using newly available anti-tuberculosis drugs, avoiding the need for hospitalization but raising vexed questions of patient ‘compliance’ with a lengthy regimen of drugs. The third stage, which set in almost as soon as drug treatment became widespread, saw the disappearance of tuberculosis from the international health agenda during the 1970s, despite evidence that it remained a very significant public health problem in developing countries. Amrith describes this third-stage decline as the result of “two seemingly contradictory phenomena – faith in the power of chemotherapy, and a lack of institutional capacity to implement it, both internationally and locally – [which] led to the decision to use drugs as the core of international policy, but to channel them through an already existing (and inadequate) infrastructure.” Thus, left with the biomedical panacea promoted by the West, but without the means to implement it properly, developing nations did not reap the benefits. Raviglione and colleagues comment that “By the late 1950s, it became clear that, unlike more developed countries, in most less-developed countries there was no decline in tuberculosis. The reasons were obvious. Mass case finding and specialized case management used in the more-developed countries could not be transferred effectively to other parts of the world; the cost was far beyond the resources of less-developed countries.” In Kenya, for example, only 24% of patients completed their full course of treatment in 1974.

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109 Ibid.


have made an impact against TB even in the absence of drugs.

Thus, even while the medical breakthroughs of the West did not prove to be a cure-all for the developing world, attention towards TB decreased in the West and at the WHO. And as WHO attention declined, so too did that of national governments. That ministries of health throughout the developing world followed the WHO's lead is illustrated by the decrease in the number of countries reporting TB statistics to the WHO: in 1970, 134 countries (with 40.5% of the world's population) reported some form of tuberculosis data to WHO; by 1975, this figure had fallen to 112 (with 35.5% of the population); and by 1979, only 61 countries (23.1% of the world’s population), less than half the number from the start of the decade, were reporting data\textsuperscript{112}.

At the same time, by the late 1970s, the international community had shifted its focus on health in developing countries to the promotion of primary health care (PHC), following the *Alma-Ata Declaration*\textsuperscript{113} and the subsequent WHO goal of “Health for All.” Most African countries soon prioritized PHC interventions such as mass vaccinations for polio and measles. TB, with the traditional vertical approach of national TB programs, was not a priority in this scheme, and faded from the agenda.

**Inconspicuous Consumption: TB in South Africa**

The history of TB in South Africa resembles that of much of the developing world, though with its own twists. It is unclear whether TB predates European contact\textsuperscript{114}, but it was certainly present in early Dutch and English settlers. Although the relatively early appearance of the Western medical tradition in South Africa means there are more historical references than for elsewhere on the continent, these references concentrate on the white community. Perversely, this racial emphasis continues well into the latter half


\textsuperscript{113} World Health Organization *Declaration of Alma-Ata*. Adopted at the International Conference on Primary Health Care, Alma-Ata, USSR, 6-12 September 1978.

of the twentieth century, as under the apartheid government “the exclusion of the majority of blacks from the statistical record [was] part of an effort to remove black health problems from view”\(^{115}\). Noting that detailed information for the population as a whole is lacking, Abdool-Karim and colleagues estimate that tuberculosis incidence “rose steadily during the 20th century, peaking first in the 1960s with over 350 cases per 100 000 population per year. A decline during the 1970s (possibly an artifact resulting from the exclusion of data from the black homelands) was followed by a resurgence in the 1990s\(^{116}\).”

It is a comment on the health policies of the apartheid era that the best records kept for TB in the black population were at the mines, where, as chronicled by historian Randall Packard in his seminal history of TB in South African, *White Plague, Black Labor*, such records were needed for monitoring the supply of workers. However, as Packard outlines, the link between mines and tuberculosis predates apartheid. Much as in Europe, industrialization in the 19\(^{th}\) Century drew workers to port cities and mines, many of whom were from disease-naive populations with low resistance to TB. As mentioned previously, the risk of TB in miners is in turn greatly heightened by high levels of silicosis. Initially, both whites and blacks were affected; the white community, however, was able to assert themselves against the mine owners and successfully obtain concessions that the black community was not\(^{117}\). Furthermore, differing policies gradually adopted for black and white labour led to a migrant black labour force living in cramped, single-sex hostels that proved an idea breeding ground for TB (just as they later would for HIV), rather than the more comfortable and permanent accommodation of white workers. According to Packard, the migrant labour system also encouraged


the spread of TB to rural areas, as repatriating sick miners to their areas of origin ensured the mines did not have to assume the expense of caring for them.

Indeed, racial politics around tuberculosis also predate apartheid. Not only was tuberculosis used as a pretext for clearing urban areas of black or coloured inhabitants\footnote{Phillips, Howard. “AIDS in the Context of South Africa's Epidemic History: Preliminary Historical Thoughts.” \textit{South African Historical Journal}, 2001 Vol.45 No.1 11-26.}, but medical interventions were based on the notion that there were fundamental differences between racial groups in their susceptibility to TB. It is likely the remnants of such views influenced Thabo Mbeki’s backlash against the medical establishment on the subject of HIV, as will be seen later. Under apartheid, interventions along racial lines were expanded; partly under the guise of public health, the choice was made to relocate rather than redress health concerns among black Africans. As Packard describes it, “the state... can be seen to have resurrected earlier models of disease control based on sanitary segregation. This time, however, it was carried out on a much greater and more tragic scale through the policy of grand apartheid\footnote{Packard, Randall M. \textit{White Plague, Black Labor: Tuberculosis and the Political Economy of Health and Disease in South Africa} 1989, University of California Press, p.18.}.”

The introduction of drug therapy in the early 1950s did decrease TB mortality in South Africa, though not morbidity. Indeed, Packard argues, the introduction of drug therapy merely provided the government with a cost-effective alternative to addressing the real underlying problems in non-white communities\footnote{Ibid. p.252.}. This is not to say that these factors were unknown; they were included in proposals on how to address TB in the black community\footnote{Benatar, S.R. “Failure of tuberculosis control in South Africa – the need for a unitary national health service.” \textit{South African Medical Journal} 1986 Vol. 70 pp. 247-248.} but they were not acted upon. Thus, as in much of the developing world, drug therapy was introduced as a complete solution, at the expense of other broader societal interventions that might also have impacted TB. Unfortunately, as elsewhere in the developing world, the implementation of drug therapy was similarly inadequate.
This was the state of affairs in South Africa by the early 1980s. By this time, TB had largely vanished from the international agenda. The end result was that TB became “the ultimate neglected tropical disease” even as it continued to take millions of lives each year in the poorest corners of the globe, and of Western countries. Thus, TB dropped off the radar just before HIV appeared.

The Rise, and Continued Rise, of HIV
Although it is now known that HIV existed prior to 1981, it is clear that it really is a new disease, at least in humans. The oldest conclusive diagnosis is in a blood sample dating from 1959; genetic analysis suggests that it first crossed over from primates to humans early in the 20th Century. The sudden emergence of HIV, and its disproportionate effects on certain groups have led to a proliferation of conspiracy theories about its origins and, in more extreme cases, its purposes. However, it was first identified at a time, and in a place, that had a large impact on the response. The resultant approach was, compared to previous epidemics, an exceptional one.

The precise meaning of the term HIV Exceptionalism has fluctuated over the years, expanding from an increased role for human rights in the response to the construction of a single-minded global program of unprecedented size and resources, though at its core it has always incorporated the idea that HIV requires a response both going beyond, and different from, traditional public health interventions. It is worth keeping in mind that, by definition, an exception can be positive or negative; as will be seen,

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122 Harrington, Mark, “From HIV to Tuberculosis and Back Again: A Tale of Activism in 2 Pandemics” Clinical Infectious Diseases 2010 Vol.50 (Suppl 3) pp.260-266.

123 To the extent that differentiation is necessary, “HIV” in this paper generally refers to HIV-1, which is responsible for the global epidemic, including in South Africa. The other type of HIV, HIV-2, is less virulent, less easily transmissible and confined largely to West Africa. Further discussion of HIV subtypes is fascinating, but beyond the scope of this paper.


the term has at times been employed as a pejorative as well.

The first printed reference appeared in 1991 in an article by Ronald Bayer entitled “Public health policy and the AIDS epidemic. An end to HIV exceptionalism?” Today, Bayer's question can be answered in the negative; 1991 was not to mark the end of HIV exceptionalism. Yet while Bayer's assertion that “[i]nevitably, HIV exceptionalism will be viewed as a relic of the epidemic's first years” has proven incorrect, his belief that “what is clear is that the effort to sustain a set of policies treating HIV infection as fundamentally different from all other public health threats will be increasingly difficult” has indeed come to pass, as illustrated by the existence of the NSP. From the first, Bayer had already identified the delicate balance between traditional public health measures and the new approach adopted towards HIV: “[W]ere the end of HIV exceptionalism to mean a reflexive return to the practices of the past, it would represent the loss of a great opportunity to revitalize the tradition of public health so that it might best be adapted to face the inevitable challenges posed not only by the continuing threat of AIDS but also by threats to the communal health that will inevitably present themselves in the future.” At the time he wrote these words, tuberculosis, a disease so closely associated with traditional public health measures, was re-emerging as one of those future threats, as will be seen later.

So what was exceptional about the response to HIV? The primary innovation was the emphasis placed on the rights of the patient. Epidemic disease has often required a scapegoat, made all the easier when it affects an identifiable, and already marginalized, group. Yet even though fears were high around the disease, and even though the groups first affected in the United States – initially homosexuals, later injection drug users and minority groups – were all groups traditionally subject to discrimination, draconian health measures were not employed. The nearly three decades of public health

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health-enforced isolation that “Typhoid Mary” Mallon had endured earlier in the century was not to be the model for HIV. Instead of preserving public health by infringing upon human rights, the resulting approach sought to do the same by promoting them. As one historical analysis concludes:

In the context of HIV/AIDS, public health and human rights each assumed-based on prior experience-that the goals of public health and the protection of human rights norms would be inherently conflictual. To perhaps mutual surprise, by the mid- to late 1980s, public health had adopted strategies which explicitly incorporated the need to respect the human rights and dignity of HIV-infected people and people with AIDS\textsuperscript{129}.

It has been widely argued that it was largely a matter of circumstances aligning themselves between health practitioners and those most affected by the disease that allowed this approach to flourish. HIV arose at a particular time in public health history. The antibiotic revolution had shown many previously fatal diseases, including tuberculosis, could be treated effectively. In perhaps the medical establishment's greatest triumph, smallpox, responsible for millions of deaths, had been declared the first infectious disease ever eradicated only the year before\textsuperscript{130}. Suddenly, a disease appeared against which medical science, even in some of the best facilities in the world, could do nothing\textsuperscript{131}. Biomedical measures, hitherto seen as able to tackle any problem that might arise, were suddenly ineffective; as a result, in the frantic search for a more fruitful alternative, there was a willingness to listen to other approaches.

And just such an approach was waiting to be heard. A primary factor affecting the efficacy of human rights advocacy around HIV was that it emerged in the gay community in the United States just as that community was undergoing massive change\textsuperscript{132}. Gay rights had recently made major advances in the United States, building in turn upon the civil rights movement. Suddenly, the gay community was


\textsuperscript{130} The declaration was made on May 8, 1980, under World Health Organization, Resolution WHA 33.3


\textsuperscript{132} For a detailed discussion, see Shilts, Randy And the Band Played On: Politics, People and the AIDS Epidemic. 1987, St. Martin's Press, New York, NY.
faced with a disease which not only disproportionately affected them, but which created a climate of fear that threatened any societal acceptance they had earned. Using lobbying skills honed in the battle for equality, they were familiar with the language of human rights, and well organized for effective advocacy. They promoted the idea that protecting the rights of patients would encourage them to seek out medical attention; by contrast, threats of public health sanctions would only drive the epidemic underground. This argument proved persuasive, and persevered over other approaches proposing the opposite tactic of mandatory testing and forced isolation of people with HIV\textsuperscript{133}. Consequently, the importance of human rights, and the rejection of rights-infringing measures became a focus early in the response, even before the disease was fully understood.

This approach soon found its way into official policy. At the time, most of the public health jurisprudence relevant to the issue had been decided around the turn of the century, and public health statutes reflected obsolete understandings both of disease and human rights\textsuperscript{134}. In the shadow of HIV, the American government conducted a review of existing public health statutes and found that, in light of advances in medical science and an increased focus on individual rights and the rights of minorities since the 1960s, they did not accurately reflect modern conceptions of either science or law\textsuperscript{135}. The rights of the individual thus became central to the response; traditional measures such as contract tracing were de-emphasized, voluntary testing initiated by the patient became the accepted standard, and privacy and confidentiality were promoted in order to encourage those infected or at risk of infection to access healthcare. A similar approach was adopted in Western Europe, which shared many similarities in both the form of the epidemic and in general norms around human rights\textsuperscript{136}.

\textsuperscript{135} Ibid.
Nevertheless, this approach was criticized for its departure from traditional public health measures. Critics have been blunt in their assessment, concluding that “the failure to apply standard disease-control methods undermines society’s ability and responsibility to control the epidemic.” This new approach was seen to value the rights of the individual over the traditional public health goal of protection of the community. The inherent social tensions behind this approach were not overlooked by critics, with one American epidemiologist noting that “we have convinced ourselves that the fight for survival can be waged in a way that is socially acceptable but not always biologically credible.”

As will be seen later, as knowledge of HIV increased, it became clear that drastic steps such as isolation of HIV-positive people were never biomedically necessary; however, an increased understanding of HIV would also lead to a reassessment of the appropriateness of the emphasis on the rights of the individual.

A further distinction must be made when talking about human rights in the context of the early American response to HIV. As with gay liberation, and the civil rights movement before it, the focus was on the civil and political rights of the individual. This included the rights to be free of arbitrary detention or harm, to privacy and confidentiality, and to due legal process, rights particularly important to the gay community that had been discriminated against for so long. At the same time, the social and economic factors fuelling HIV were felt predominantly among intravenous drugs users and minority communities who were less well organized and less able to assert their needs. Consequently, there were fewer voices calling for assertion of these rights.

Civil society thus played a key role in the initial response to HIV, just as they would, as will be seen, in South Africa some years later. Just as importantly, they affected which human rights were brought to the table. At the same time, civil society also had an effect on dissemination of medical

knowledge, hitherto the domain of the medical practitioner. Given the lack of knowledge of the disease at the time, civil society promoted HIV education; both patients, who were often well educated as well as highly motivated and organized, and their doctors found themselves learning about HIV at the same time, putting them on a more equal footing than the traditional doctor-patient relationship. This was in stark contrast to TB programs where the existence of a biomedical cure and the predominantly disempowered patient population meant that the emphasis was on that cure, and the patient's role was to accept the cure as given. Thus HIV was a further challenge to the traditional public health approach, which had provided health practitioners the secondary benefit of positioning them as experts to define and “own” the problem. The absence of effective treatment would, in combination with the human rights emphasis, further this educational approach, as public education about HIV was crucial not only to prevent the spread of infection, but to show the broader population that they were not at risk from shaking hands or sharing toilet seats. It also meant that prevention and other information about HIV was focused on responsible individual behaviour, such as condom use. Thus, protection of the rights of the individual was combined with efforts to show why protecting these rights did not infringe upon those of the general public to remain free from illness. Although it has subsequently been argued that this approach meant that large amounts of money were wasted targeting people who were never at risk instead of being spent on more effective tailored interventions for high risk groups, it also promoted the responsibility of all individuals in society to take precautions, rather than fuelling stigmatization by further linking specific groups to HIV.

Thus, a sui generis approach was adopted towards HIV, one which displaced years of more coercive public health practice in favour of the rights of the individual. Nevertheless, even many of exceptionalism's critics recognized that it suggested potentially useful new directions for public health.

although they believed it had travelled too far down that path. Casarett and Lanlos, two long-time critics, acknowledged that “The question we must face...is whether the treatment of AIDS will be brought in line with the treatment of other diseases or whether the treatment of other diseases will come to resemble the treatment of AIDS. The latter solution is attractive and is worth pursuing to the extent that scarcity permits.” Kevin de Cock, whose own criticisms of exceptionalism will be discussed later on, outlined some the advances made through an exceptionalist approach: “[T]he exceptional status of HIV/AIDS has enhanced communication between doctors and patients and has made medicine less formal. Autonomy has been strengthened and patients have become more involved in decisions about their own care. Individuality has been more readily acknowledged, respect for informed consent and confidentiality has increased, and patient advocacy has emerged as a force for change.”

However, it is the observation that “[t]he chances of utilizing innovations developed in connection with AIDS for the modernization of health policy in other fields of prevention and patient care vary from country to country with the degree to which AIDS exceptionalism has been institutionalized and the distance of these innovations from medical, therapeutic events” that is most worth bearing in mind throughout the remainder of this paper.

**Global Problem...Global Solution?**

Although HIV originated in Africa, and the continent notoriously bears the brunt of the epidemic, it played a minimal role in the initial response. As with TB, its early prioritization was impacted by the WHO Health for All program. In 1985, Halfdan Mahler, the Director General of the WHO, dismissed HIV as a dangerous diversion from the focus on primary health care that had become the main priority in Sub-Saharan Africa, stating: “[I]f African countries continued to make AIDS a 'front-page' issue, the

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objectives of health for all programmes by the year 2000 would be lost... AIDS is not spreading like a bush fire in Africa. It is malaria and other tropical disease that are killing millions of children every day." A lack of resources ensured that data on HIV was scarce; until widespread use of sero-prevalence studies, it is likely that many cases were overlooked and attributed to some other illness.

Furthermore, a reluctance of some African leaders to move quickly on a disease that raised issues around sexuality and other taboo topics was also a factor. As a result, for a variety of reasons, HIV was not a priority for Africa, or those funding health on the continent, in the years exceptionalism was developing. Even by 1990/91, when the African epidemic was well under way, only 6% of the total global spending for HIV prevention went to the developing world.

Thus, by the time national governments and international bodies finally did turn their attention to HIV in Africa, the Western powers dominating international health discourse already had strategies prepared and ready for deployment, rooted largely in the exceptionalist approach to their own epidemics. The expansion of exceptionalism to become the global standard can largely be attributed to Jonathan Mann, the first head of the WHO Global Program on AIDS (GPA). Historian John Iliffe describes him as “the most important figure in the history of the AIDS epidemic.”

Mann's tenure ran from 1986 until 1990. Under Mann's leadership, the GPA not only propagated the exceptionalist approach towards human rights, but refused to provide support for discriminatory activities, such as laboratory resources for mandatory testing. By 1987, the World Health Organization had formally included non-discrimination towards HIV-positive people in the first Global AIDS Strategy; this was the first time that concern about the human rights of infected people became

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an integral part of a strategy to control an epidemic\textsuperscript{150}. This policy also defined HIV in terms of individual risk behaviours as had been done in Western countries. It was this approach to HIV and human rights, propagated by the WHO, that became the \textit{de facto} global norm. Iliffe describes the spread of these strategies as “one of the most striking modern examples of globalization\textsuperscript{151}.”

\textbf{Rights and Wrongs}

As with many aspects of globalization, the question was soon raised whether what was deemed appropriate for the West was similarly so for the rest of the world. Once again, an approach rooted in universal human rights was not viewed by all to have universal applicability. On one hand, the stringent protections of the civil and political rights of HIV-positive people had fewer practical implications in much of Africa. Even if governments seriously considered rights-infringing measures like forced isolation, decrepit health systems and a general lack of resources would have proven a serious impediment to any attempt to put such measures into force\textsuperscript{152}. Similarly, on a continent where no sitting leader was ousted peacefully at the ballot box until 1991\textsuperscript{153}, civil and political rights of the individual were not a priority for most governments. On the other, a lack of civil and political freedoms was also not the primary issue affecting the vulnerability of most citizens to HIV. In countries where much of the populace lacked basic health services, an approach designed to safeguard the civil rights of an oppressed minority was not a perfect fit for a generalized heterosexual epidemic. A review in the WHO Bulletin discussed these issues as follows:

Historically, human rights approaches in Western countries have tended to privilege civil and political rights over socioeconomic and developmental rights. In the early years of the epidemic, this prompted a focus on discrimination against people living with


\textsuperscript{152} Ibid. p.66. The only country to effectively implement traditional public health measures for HIV, including mandatory testing and isolation, was Cuba; whatever the verdict on the appropriateness of these measures, it cannot be denied that they were only possible because Cuba mobilized the necessary resources to carry them out.

\textsuperscript{153} “A good example: One of Africa’s most successful countries sets a trend that more can follow” \textit{The Economist} Oct. 22/2009. The country in question was Benin.
HIV/AIDS and on vulnerable groups. For many developing countries, however, such a
narrow concept of rights fails to engage with the full range of social, political and
cultural factors that underlie vulnerability to HIV and responses to AIDS. It is not
surprising, therefore, that practitioners in developing countries may be sceptical of

Furthermore, social circumstances made it difficult in some cases to even bring many of the issues
around HIV to the discussion table. This stems in part from the differing social contexts in which the
epidemic arose. In North America and Western Europe, the years prior to the emergence of HIV
brought a series of social changes, including the rise of feminism and gay rights. Thus, these countries
were better prepared to deal openly with issues concerning sex and sexuality than societies that had not

Other universal values turned out to differ in interpretation; for
instance, even well-meaning attempts to prioritize women's issues may have suffered from a model that
positioned “white women from the professional middle classes of the United States and Western

Perhaps the biggest difference, however, was in perceptions of the balance between the rights of
the individual and of the community. Broadly speaking, the Western emphasis on individual rights
clashed with African perspectives that valued the interests of the community over that of the individual.
This is not to say that the West should be treated as uniformly individualistic, or Africa uniformly
communal; differences occurred within these regions as well. For instance, stringent measures
restricting individual freedom under Sweden's Communicable Diseases Act proved largely
uncontroversial in that country, something attributed to the “‘Swedish character' emphasizing collective
good.”\footnote{Danzinger, Renee “HIV testing and HIV prevention in Sweden” British Medical Journal Jan.1998 Vol.316 pp.293-295.} However, the idea that a more communal focus is common in Africa is borne out in
documents like the *African Charter on Human and Peoples' Rights*, in which the rights of the individual are explicitly balanced by duties towards others. For instance, under Article 27(2), “The rights and freedoms of each individual shall be exercised with due regard to the rights of others, collective security, morality and common interest”¹⁵⁸. This being the case, it has been argued that in the African context, all human rights associated with HIV have to be exercised with due regard to collective and common interest¹⁵⁹.

Nevertheless, with technical expertise and financial backing firmly located in the Western camp, most countries soon followed suite. It is in this context that Iliffe concludes:

Mann's strategy, in fact, could be seen – and later in the epidemic sometimes was seen – as an example of intellectual imperialism, of globalization at its most arrogant.... his human rights were in reality the rights only of patients with no concern for the rights of others; the emphasis on individual rights propounded by American's homosexual minority was irrelevant to a mass heterosexual epidemic; and no Western government faced with an epidemic on the African scale would have dreamed of maintaining such a policy.¹⁶⁰

**South Africa: New Nation, New Disease**

At the same time, to define the situation as that of a Western solution being forced upon an African problem necessarily lacks nuance. In the South African context at least, the evolution of a human rights-focused approach to HIV was influenced as much by domestic factors as foreign ones. At the same time, the South African response, and indeed the South African epidemic, differed in a number of ways from its surrounding countries on the path to a rights-focused response.

Information on the early years of the South African epidemic is sparse; as Nathan Geffen writes, “Apartheid's oppressive environment meant that few people were willing to fight an epidemic that mainly affected marginalized people, and so there are not many written accounts from that time.”¹⁶¹

Nevertheless, while it is necessary to be cautious about interpreting the early published history of HIV in South Africa as one that reflects the entire situation, rather than the focus of the medical community and its resources on the dominant white minority, it nevertheless appears that, perhaps uniquely within Africa, the initial pattern of the HIV epidemic was the same as that in North America. Paralleling North America’s “Patient Zero”, Gaetan Dugas\textsuperscript{162}, the first two diagnosed cases were also white male flight attendants\textsuperscript{163}. The first of these died August 26, 1982\textsuperscript{164}. Published in July of 1983\textsuperscript{165}, these were the first published case reports in South Africa, although AIDS had received coverage in the \textit{South African Medical Journal} at least as early as an editorial in February 1982\textsuperscript{166}. That the observed pattern resembled that in the West, with the majority of cases occurring in white homosexual males, is seen in the following contemporary review from the late 1980s:

\begin{quote}
The total number of AIDS cases seen, as at 22 June 1989, is 231 with a mortality rate of 57%. These patients were: homosexual or bisexual men 176; heterosexual 35; blood transfusion-related 14 and 10 with haemophilia. One intravenous drug user has now been identified. The sexual distribution is male 206 and female 25. The ethnic distribution is whites 181, blacks 40, coloureds 8 and Asians 2\textsuperscript{167}.
\end{quote}

Tellingly, this information is included in a postscript, added just prior to publication. The main body of the article, going up to December of 1988, records only 166 cases\textsuperscript{168}. Based on the demographic believed most at risk, South Africa's early response similarly reflected a more Western model. When AIDS training, information and counselling centres (ATICCS) were established in major cities from


\textsuperscript{168} Ibid.
1988, they were located in white areas, with, initially, a largely white clientele\textsuperscript{169}. This response was itself organized in large by white gay activists; the socially conservative South African government did not think highly of gay rights, and homosexual activity was a criminal offence.

Nevertheless, the review above also cautioned that, if trends continued, “we can anticipate an 'African-type' HIV pattern in South Africa in the near future\textsuperscript{170}.” While the warning note it sounds on HIV in the black population seems unsurprising in retrospect, what it considers “the most alarming development in 1988” does have the ability to shock in light of the scope of the disease in South Africa today. This alarming development? “[T]he marked increase in cases in the black population from 5 in 1987 to 17 in 1988\textsuperscript{171}.” This warning proved prophetic, as by 1990 heterosexual transmission was the dominant mode of transmission of HIV\textsuperscript{172}. This shift was in actuality the result of parallel epidemics, with the strain of HIV in the homosexual epidemic being the same as that found in the gay communities of Europe and North America, while the strain affecting heterosexual blacks was the same as that found in the heterosexual epidemic already in full swing elsewhere in Southern Africa\textsuperscript{173}. Like TB, the latter spread in large part through migrant labour, as well as along increasingly busy transport routes\textsuperscript{174}.

South Africa's response to the epidemic also developed differently due to the country's isolation from the international community, particularly given that the HIV epidemic coincided with the peak of the international anti-apartheid movement. However, the roots of this separation began much earlier; South Africa had lost its status as a voting member of the WHO in the 1960s. Yet despite the delay in recognizing the broader epidemic, and despite South Africa's isolation from the larger world

\textsuperscript{171} Ibid.
\textsuperscript{174} Ibid.
community, the human rights component of South Africa's first truly national HIV policy was to look very similar to that envisioned by Mann.

In part, this occurred because WHO policy came in through the backdoor just as the world community was applying the rights-based approach developed in the West to the generalized African epidemic. However, its entry was only possible due to South Africa's domestic struggle for human rights. In exile, the African National Congress (ANC) had become aware of HIV, and had participated in drafting the 1990 *Maputo Statement on HIV and AIDS in Southern Africa* which acknowledged that the “rights of people with HIV disease, as with any other health condition, must be firmly recognized.” Later, an early gesture of reconciliation after the ban on the ANC was lifted was its inclusion in the 1992 conference that led to the launching of the National AIDS Committee of South Africa (NACOSA), tasked with formulating an AIDS Plan for South Africa. The team tasked with writing the Plan drew upon knowledge and experience from both industrialized and other African countries, resulting in a plan that was “drafted with WHO assistance and embodied all the current international priorities.”

It was also drafted at a time when the South African Bill of Rights was being formulated, and equality and democracy were on the horizon. As a result, the first AIDS Plan in South Africa emerged in a burgeoning climate of human rights, just as had occurred in the United States for different reasons the previous decade. Driven by this, “[i]t went further than the generation of WHO-inspired Medium Term AIDS Plans of the time to embrace the sexual rights of women as a cross cutting theme and to accord people living with AIDS a key role in AIDS policy development and implementation.”

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as Howard Phillips notes, the first disease in South Africa's history to emerge in a climate where human
rights were a priority\textsuperscript{179}. The finalized Plan\textsuperscript{180} was presented to the new ANC government in 1994. With
an estimated HIV prevalence that was lower than neighbouring countries at just over four percent\textsuperscript{181}, a
plan designed by local and international experts, and most importantly, a sense of optimism for the
fledgling democracy, it seemed South Africa was prepared to meet the threat of HIV.

\textbf{An African Problem and a Problematic African Leader}

South Africa thus entered democracy with a WHO-approved AIDS plan with an emphasis on human
rights. This did not translate into a great deal of success against HIV. By 1998, there was widespread
agreement that “the National AIDS Plan was not implemented as expected, and has turned out to be not
much more than 'a neat book on the shelf'\textsuperscript{182}.” This failure of implementation was not due to insufficient
funds; between 1994 and 1997 the AIDS program consistently under-spent its allocated budget\textsuperscript{183}. As
Schneider discusses, it became apparent that expectations of the state's ability to lead and co-ordinate
the response to AIDS were not being met. As a consequence, the National AIDS program revised its
priorities, shifting from an implementation function to one of drawing up guidelines, developing
capacity and co-ordination\textsuperscript{184}, the same role still played by today's NSP.

These failings of governmental leadership were in stark contrast to Uganda, where leadership at
the highest level has been widely heralded as a key factor in that country's success in reversing their
epidemic\textsuperscript{185}. So what went wrong? Although Nelson Mandela's leadership is laudable on many counts,

\begin{flushleft}
\begin{thebibliography}{99}
\bibitem{Ibid} Ibid.
\bibitem{Ibid} Ibid.
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launching an effective response to HIV is not one of them. But if his failures came largely through inaction, the same cannot be said about his successor. It is impossible to discuss HIV in post-apartheid South Africa without some reference to AIDS denialism and its consequences, particularly under the stewardship of President Thabo Mbeki and Health Minister Manto Tshabalala-Msimang. Mbeki largely rejected the international consensus on HIV, famously denying the link between HIV and AIDS in favour of a broader socioeconomic explanation of the condition. There has been considerable speculation as to why Mbeki adopted these views and continued to hold them in the face of criticism at home, abroad, and increasingly within his own government. While a proper analysis of denialism under Mbeki is beyond the scope of this paper, his strong feelings about what he considered to be a racist conception of why HIV predominantly affected Africans, together with personality traits that made him reluctant to reverse his position in the face of criticism, are widely thought to have led to his intransigent stance on the issue. Whatever the reasons however, the impact of his views, particularly his refusal to accept HIV as the cause of AIDS, proved considerable.

Denialism influenced HIV policy throughout Mbeki’s presidency, although after he withdrew from public comment on the matter the public face of this view was generally Tshabalala-Msimang. Even when pressured into adopting policies in line with international standards, the government maintained reservations about their content; rather than fully accepting the link between HIV and AIDS, the South African government operated on the “assumption” that HIV causes AIDS until September 2002, which became a “premise” until March 2003. This reluctance evidenced itself in foot-dragging at best, and outright obstructionism at worst.

This gap in leadership opened the door for civil society to fill the void. Unlike during the

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drafting of the initial AIDS Plan, however, when a wide range of civil society actors, including the now-governing ANC, worked side-by-side in the rosy glow of the activism that had brought apartheid to its knees, the relationship between comrades was no longer one of camaraderie. Shortly after the AIDS Plan was released, the activists who had come together in the climate of independence began to feel left out. At the 1996 World AIDS Conference in Vancouver, one advocate lamented “There is a deep sense of loss in the NGO community which feels it is no longer involved in the struggle to support people with AIDS in South Africa”\(^\text{189}\). The sidelines must have been full; that same year, a national database listed a total of 661 organizations with an interest in AIDS\(^\text{190}\). As Schneider notes in her 1998 analysis of the failings of the AIDS Plan, “the presence of a civil society willing to challenge and provide a critical mirror to government on an ongoing basis is key to the medium and long term success of AIDS prevention\(^\text{191}\).” The organization that would do the most to play this role and fill the leadership void would be formed later that same year.

The catalyst, ultimately, was the issue of antiretroviral drugs. It was here that denialism was to have its most regrettable effects; ART was variously posited as an unnecessary and expensive distraction from the real problem, as a money-making conspiracy by the pharmaceutical companies, or even the real cause of the symptoms of AIDS\(^\text{192}\). In turn, the struggle for access to ART became the defining moment in HIV intervention in South Africa. It solidified the importance of human rights in the response to HIV. It heralded a new role for civil society in advocating for these rights, and the judiciary in upholding them. It is also the moment when South Africa moved to the global forefront of the HIV response. It was not always a world, however, that shared the same views.

\(^{189}\) Rossouw, Rehana “Zuma's revenge” Mail & Guardian (Johannesburg) - July 26, 1996.


\(^{191}\) Ibid.

Chapter 4: Universal Rights But Not Universal Access

The Expansion of Exceptionalism

By the mid-1990s, HIV remained exceptional, but the exceptionalist approach to human rights had established itself as the rule internationally. In 1995, the UN Commission on Human Rights clarified that discrimination on grounds of serostatus, real or presumed, is prohibited by existing international human rights standards. But as HIV became an international issue, the meaning of exceptionalism similarly expanded to encompass the global response to the disease and the resources dedicated to it. Casarett and Lanlos describe this expanded definition: “During the past decade, medical therapy for AIDS has become more effective but also prohibitively expensive. A medical tragedy has been transformed into a financial crisis, and society has responded by establishing special programs and sources of funding for AIDS. These manoeuvres parallel earlier approaches to HIV testing and reporting that have collectively come to be known as 'exceptionalism.'”

Interestingly, the net result of this shift in the definition was to increase criticism of exceptionalism while de-emphasizing those rights that had not formed its initial core, in this case primarily the socioeconomic rights. Critics argued HIV received too much funding, while other diseases received too little; by extension, people with HIV were overprivileged at the expense of those with less “popular” diseases. A story that has resurfaced in a number of guises always ends with the same punchline: HIV is a fashionable cause, while you can't talk about diarrhoea at a cocktail party. The expanded definition of exceptionalism led to allegations of the creation of an “AIDS Establishment”, made up of doctors, NGOs, consultants, bureaucrats and others with a vested interest in spending money on HIV, resulting in a grossly inefficient use of resources, an accusation later

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193 UN Commission on Human Rights, Resolution on HIV/AIDS, Res. 1995/44.
publicized in popular books by Elizabeth Pisani\textsuperscript{196} and Helen Epstein\textsuperscript{197}.

There is little question that some of the money allocated to HIV was, and continues to be, ill-spent. Similarly, there is little doubt that it overshadows other health conditions, and that in some cases, a limited pool of donor funds ensures HIV programs benefit at the expense of others\textsuperscript{198}. Perversely, however, this shift arose at the same time that effective treatment finally emerged for people with HIV. The first HIV drug had appeared in 1987\textsuperscript{199}; however, it was in 1996 that HAART (Highly Active Antiretroviral Therapy), the first truly effective treatment, was announced at the International AIDS Conference in Vancouver\textsuperscript{200}. Soon, effective combination drug regimens were available in Western countries. Despite the fact that effective, life-prolonging treatments existed, however, they were not available to those in greatest need, in the countries hardest hit by the epidemic. One year of treatment initially cost roughly $20,000, placing it out of reach of many even in the West without assistance. The right to effective treatment became one afforded, in all senses, only to a privileged few. Where the right to access to medical care was concerned, Africa thus became the exception. It was argued that drugs were not affordable in the African context, or that the drugs would not work in the African environment. Former UNAIDS Director Peter Piot describes how, at the 2001 UN Special Session on HIV/AIDS, all Western nations present except France “totally opposed mentioning the word antiretroviral therapy and to have a target or a goal on treatment for people living with HIV”\textsuperscript{201}. A typical argument along these lines, from the premise that “[i]n the face of resource scarcity and urgent social needs, governments and donors need to prioritise” is found in \textit{The Lancet} in 2000:

\begin{thebibliography}{9}
\bibitem{198} Although for an interesting examination of this issue, see Shiffman, Jeremy “Has donor prioritization of HIV/AIDS displaced aid for other health issues?” \textit{Health Policy and Planning} 2008 Vol.23 pp.95–100.
\end{thebibliography}
Highly active antiretroviral therapy is not affordable on a large scale in less-developed countries either privately or by government, nor is it a technology that most poor people could adhere to or that existing health systems in poor countries are equipped to support. Even if the drugs were cheap, this type of therapy would probably not be cost-effective as implemented for most patients compared with treatment of opportunistic infections because of problems with non-compliance and erratic supplies of drugs\textsuperscript{202}.

Similar sentiments were expressed with considerably less tact by USAID Director Andrew Natsios, who famously told the US Congress “[Africans] do not know what watches and clocks are. They do not use Western means for telling time. They use the sun. These drugs have to be administered during a certain sequence of time during the day and when you say take it at 10:00, people will say what do you mean by 10:00?\textsuperscript{203}” Natsios' comments highlight the fact that beneath legitimate concerns about government capacity, sustainability and health infrastructure lay a series of assumptions about the patients themselves and their ability to take care of their own health. It was argued that programs should focus entirely on prevention, or even that drugs should be denied Africans on the grounds that non-adherence would lead to the creation of drug-resistant HIV. In other words, “Treatment as an essential part of a comprehensive response to HIV/AIDS in developing countries was viewed as impossible, or even irresponsible\textsuperscript{204}.” Thus instead of focusing on the very real obstacles to getting ART to patients in Africa, the implication was that there was little point in addressing such issues since patients would be unable to use ART successfully anyway. The failures of African states were conflated with failures of Africans.

As it turns out, these assumptions were unfounded. A meta-analysis of ART adherence studies in both Sub-Saharan Africa and North America demonstrated considerably higher levels of adherence


\textsuperscript{204} Schwartländer, Bernhard; Ian Grubb, Jos Perriëns “The 10-year struggle to provide antiretroviral treatment to people with HIV in the developing world” The Lancet 2006 Vol.368 pp.541–46.
among African patients\textsuperscript{205}. Indeed, with good adherence being defined as taking 95\% or more of drugs correctly, 77\% of the African patients, versus 55\% of North Americans, demonstrated good adherence\textsuperscript{206}. Although like most meta-analyses it does not always reflect the subtleties of the individual studies covered, it nonetheless demonstrates not only that adherence is possible in Sub-Saharan Africa when ART is made available, but raises questions about the effectiveness of the North American programs which largely escaped scrutiny even as ART was described as inappropriate for Africa. Similarly, despite the argument advanced in South Africa that “the disproportionate emphasis on ART in public debates could result in complacency and a false perception that there is a panacea for HIV and AIDS\textsuperscript{207},” ART programmes in the West have not in practice been greatly affected by studies showing that in some instances people were less likely to practice safe sex now that HIV/AIDS was a treatable condition\textsuperscript{208}.

In fact, where drug resistance is concerned, some of the relevant factors were actually more favourable for patients in Africa: far fewer patients had been exposed to previous sub-optimal drug regimens compared to their Western counterparts\textsuperscript{209}. These treatment-naive patients had thus not developed any drug resistance, and would be initiated from the beginning onto recommended multi-drug therapy, rather than developing resistance through the years of monotherapy many had undergone in the West. If given access to the drugs, Africans were at least as capable of benefiting from them as anyone else, if not moreso.

\textsuperscript{205} Mills, Edward J; Nachega, Jean B; Buchan, Iain; Orbinski, James; Attaran, Amir; Singh, Sonal; Rachlis, Beth; Wu, Ping; Cooper, Curtis; Thabane, Lehana; Wilson, Kumanan; Guyatt, Gordon H; Bangsberg, David R. “Adherence to Antiretroviral Therapy in Sub-Saharan Africa and North America: A Meta-analysis” The Journal of the American Medical Association Aug. 2006, Vol. 296 Iss. 6 pp. 679 – 690.
\textsuperscript{206} Ibid.
\textsuperscript{208} Kelly, Jeffrey A; Raymond G. Hoffmann, David Rompa & Michelle Gray” Protease inhibitor combination therapies and perceptions of gay men regarding AIDS severity and the need to maintain safer sex” AIDS 1998 Vol.12 pp.F91–F95.
Thus, although adherence and drug resistance are important considerations in any ART program, they became excuses for inaction. As Moatti and colleagues concluded, “referring to these issues of resistance and adherence as an argument to withhold or delay access to HAART in developing countries implicitly imposes a double standard of thinking that should be rejected: arguments that are not even considered in the north serve as dogma to limit access to treatment in the south.” Amir Attaran, one of the authors of the meta-analysis above, made the following additional observation getting to the root of addressing adherence issues:

In rich countries, the study failed to identify any obvious “big fix” that could turn non-adherent patients into adherent ones. On the other hand, for developing countries, “financial constraints” towered above the other reasons why poor patients may fail to adhere to ART. That is cruelly ironic, because the same international development policy makers who rejected the idea that poor people could adhere to ART also worked for financial donors such as USAID and the World Bank, and their passionate arguments against ART stalled the delivery of the one variable that helps adherence—money.

Exceptionalism had initially expanded in large part based on the idea that human rights were universal, and should thus apply to everyone equally. By extension, benefits gleaned from the exercise of these rights should be measured the same way, and such measurement must recognize that there are no perfect outcomes. As Kuritzkes notes: “Inevitably, drug resistance will occur in some patients. This eventuality should be anticipated, but should not be taken as evidence of programmatic failure. The success of antiretroviral therapy in resource-poor countries should be judged by the same criteria as those applied in the developed world: measurable reductions in AIDS-related morbidity and mortality.” In South Africa TAC partnered with Medecins Sans Frontieres for a project in the Khayelitsha township of Cape Town to demonstrate that ART could be effective in a low-resource setting.


environment. The results bore this out, with an early report on the project reporting as follows:

This study demonstrates that the high levels of adherence required to implement successful ART were achieved in an African cohort without formal adherence intervention. Factors impacting on adherence and virologic outcomes elsewhere were similarly reflected in this cohort. Clinical and virologic benefits were maintained after 1 year. Most importantly, low socioeconomic status was not a barrier to success. Individuals with HIV disease, who could potentially benefit from ART, should not be denied access based on otherwise unsubstantiated expectations of poor adherence. Thus, the issue of whether Africans could benefit from ART was answered in the affirmative; this helped focus the response on what actually needed to be addressed. That infrastructure and distribution systems for ART are lacking in Africa is unquestionable, but it is only one part of the ART issue, and it is one that is resolvable. As International AIDS Society President Joep Lange noted, “if we can get cold Coca-Cola and beer to every remote corner of Africa, it should not be impossible to do the same with drugs.” The undeniable difficulties in resolving this issue should not spill over into impugning the ability of people to use drugs once those drugs are reliably available. As Edwin Cameron concludes, “It is patronising to presume that living in adversity disqualifies people from taking responsibility for their own lives by taking medicines properly. All medicating patients – rich and poor, African and non-African – need information, training, encouragement and support. They all deserve it, as well as the medications that make this backup necessary.” Thanks to the efforts of civil society, such an approach would be adopted in South Africa.

The War of ART
At the beginning, ART in South Africa was more fantasy than reality. Prices that made a healthy profit in the rich countries of the West were not only unaffordable but completely unfathomable to the majority of those most in need of treatment; like a science fiction film, the rich could buy a magic pill

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that would extend their lives by years, while the poor could only watch. Justice Edwin Cameron, the first public figure in South Africa to publicly announce his HIV status, and one who has been very open about the fact his privileged position allowed him access to antiretroviral treatment long before the vast majority of his countrymen, noted that even as a high court judge, in the highest strata of South African society, antiretroviral drugs cost 1/3 of his after-tax monthly income when he started taking them in 1997\textsuperscript{216}. It is here, in the midst of what has been called international “treatment-apartheid\textsuperscript{217}”, that South Africa would take a leadership role in the provision of ART. It was not the government, however, that would assume this role, but civil society. The most important group to step into the leadership void left by the government was the Treatment Action Campaign (TAC). The first action by TAC took place on December 10, 1998. A small protest consisting of only ten people, TAC's accompanying statement laid out priorities that would guide future campaigns in the years to come:

The National Association of People Living with AIDS (NAPWA) has initiated the Treatment Action Campaign to draw attention to the unnecessary suffering and AIDS-related deaths of thousands of people in Africa, Asia and South America. These human rights violations are the result of poverty and the unaffordability of HIV/AIDS treatment. The Treatment Action Campaign calls on the minister of health... to meet immediately with NAPWA and HIV/AIDS organizations to plan for resources to introduce free AZT an antiretroviral drug] for pregnant mothers with HIV/AIDS. TAC also calls on government to develop a comprehensive and affordable treatment plan for all people living with HIV/AIDS\textsuperscript{218}.

Although initially under the banner of NAPWA (National Association of People With AIDS), a government-funded civil society group that had formed in 1994, TAC soon split from its parent body over differences around NAPWA's more cautious approach to dealing both with government and pharmaceutical companies\textsuperscript{219}. This willingness to be confrontational was one of the first factors setting

\begin{footnotesize}
\begin{enumerate}
\item Schwartländer, Bernhard; Ian Grubb, Jos Perriëns “The 10-year struggle to provide antiretroviral treatment to people with HIV in the developing world” \textit{The Lancet} 2006 Vol.368 pp.541–46.
\end{enumerate}
\end{footnotesize}
TAC apart from other civil society organizations concerned with HIV; founding member Zackie Achmat famously refused to take ART until it was available to all South Africans.

As Seckinelgin suggests, although NGOs have played a key role in the response to HIV throughout Africa, these roles have largely been carried out as service providers for international policy makers. Since such organizations are dependent on international funding, their activities are guided by the priorities of their funders; their resulting service delivery role is incompatible with a critical advocacy role which might jeopardize this funding relationship. NGOs thus gradually internalize certain ways of relating and thinking that are independent of their ostensible connection to the communities they serve. Observes Seckinelgin: “Apart from the Treatment Action Campaign in South Africa, this [critical advocacy] model is not observable in the region.”

A second factor setting TAC apart is that it is aspired to be a genuine mass movement. Other organizations in South Africa had addressed human rights and HIV before but had never achieved mass support. For instance, the AIDS Consortium, a group that formulated the Charter of Rights on AIDS and HIV in 1991, initially comprised primarily human rights lawyers, gay men, and health professionals. Although that document was a progressive one which included the socioeconomic right to public benefits among a range of civil and political rights, Heywood speculates the makeup of the organization had the drawback of perpetuating “the perception that AIDS was a disease which affected mainly wealthy, gay white men.” Thus, although it began as a few middle-class people with working-class roots, TAC consciously expanded into poor black communities where HIV was most

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221 Ibid.
222 Ibid.
224 Ibid.
serious; at its peak, TAC had roughly 17,000 members\textsuperscript{226}. This helped set the stage for all South Africans to have a voice in discussions affecting them. Johnson describes the resulting situation as follows:

\begin{quote}
[A] sort of “rainbow politics” around AIDS where white, middle-class legal, research, and gay communities have found a degree of common ground with poor black communities, where very disparate organizations with differing constituencies and political goals cooperate with one another. This burgeoning movement has features of a liberal rights based movement, strongly influenced by white, middle-class males and focusing on legal rights that can be guaranteed by the courts and the rights of individuals to treatment. However, at times it also challenges liberal understandings of rights, promoting a more socialist or nationalist understanding of rights that focuses on equality of access and collective rights and is grounded in the discourse of the liberation struggle\textsuperscript{227}.
\end{quote}

This mass mobilization, and the issue of ART in particular, had another profound effect on HIV discourse in South Africa. Through coverage in the media, and more importantly through education campaigns by TAC and other organizations, more South Africans became informed about the issue and how it affected them. Achmat comments: “Treatment literacy is the most important work of the TAC. This is also the most sustained and developed programme of the organization\textsuperscript{228}.” Education programs went directly to the core of the comments by Natsios, and by Tshabalala-Msimang who had similarly stated ART would not be effective in the South African context because “many do not understand the importance of completing a course of drug therapy. People don't have watches\textsuperscript{229}.” Phillips makes the following observation of South Africa at the time: “The fact that AZT is an acronym probably as familiar in Mtubatuba as in Mayfair is a product of this process of the biomedicalization of South African society, which means that, in terms of the degree of acceptance of biomedicine, the HIV/AIDS epidemic takes place against a background markedly different from that of earlier epidemics in South

\begin{flushright}
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While treatment literacy and education programs may have been TAC's defining feature at home, the one for which TAC garnered the most fame internationally was its willingness to use a combination of action on the streets and in the courts to enforce the rights it advocated for, wielding South Africa's Bill of Rights against all comers, including the ANC government so instrumental in its drafting. TAC's first campaign to yield large dividends was against the pharmaceutical companies. In 1997, the South African government amended the *Medicines and Related Substances Control Act* to permit importation of generic drugs, with the intent of making essential medicines more affordable. When the Pharmaceutical Manufacturers Association (PMA), alongside 40 multinational pharmaceutical companies, challenged this amendment, it also did so, interestingly enough, under the Bill of Rights, in this case the property rights under Section 25. The subsequent case, which TAC joined as *amicus curae*, thus pitted property rights against that of access to healthcare; more precisely, the excessive prices of antiretroviral medicines were claimed to create a barrier to access that should justifiably limit the property rights of the pharmaceutical companies. This notion of patient rights versus patent rights garnered international attention. In the resultant storm of bad publicity, the PMA withdrew their action in April 2001. The bad publicity also led pharmaceutical companies to offer drugs at lower prices. Thus, TAC chipped away at the first barrier to ART, the high cost. TAC, often with partner organization the AIDS Law Project, would continue to litigate against pharmaceutical companies in order to promote access to drugs on a number of occasions and in a number of fora.

It came as a surprise to TAC when, after victory against the pharmaceutical companies, the government failed to take further action in ensuring that antiretroviral drugs were made available. Thus,

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232 For instance, in front of the Competition Commission in *Hazel Tau and Others vs GlaxoSmithKline South Africa (PTY) LTD and Others*, 1998.
the second obstacle was the government of South Africa itself, then at the height of its denialist tendencies. Much of this dispute took place once again around the right to access to healthcare, and the obligation it created by which “the state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realization of each of these rights”\textsuperscript{233}. The sticking point proved to be financial, with the state claiming ART was far from “within its available resources”. A previous attempt to enforce a Constitutional right to access to healthcare in a kidney dialysis case had previously failed on the grounds that available resources were limited\textsuperscript{234}. The cost of providing highly expensive ART to millions of people, potentially for decades, indeed seemed beyond the means of the government, even as evidence mounted it would be cheaper to provide ART than to provide healthcare to HIV-positive people once they became sick, even without factoring in the economic benefits of a healthy workforce\textsuperscript{235}.

In the end, the resource issue was downgraded in part by approaching ART provision one step at a time. The crucial victory was in the provision of appropriate ART to HIV-positive pregnant women in order to prevent mother-to-child transmission (MTCT). In 1998, it was estimated that 70,000 infants were born with HIV\textsuperscript{236}. Rather than requiring years, or decades, of treatment, a short course of ART drastically decreased the chance of transmission. The dividend, a healthy infant, seemed a worthy return on the short-term investment required, yet the government failed to move forward on providing ART even after successful pilot projects were carried out. TAC began demonstrating for ART for MTCT in 1999; following a lack of response from the government, TAC took the Health Minister to court to force her to allow facilities in the public health system to provide suitable ART to pregnant women with HIV. In 2002, the Constitutional Court unanimously agreed with TAC's arguments,

\begin{itemize}
\item \textsuperscript{233} Constitution of the Republic of South Africa, 1996, S.27(2)
\item \textsuperscript{234} Soobramoney v Minister of Health (Kwazulu-Natal)  BCLR 1696 (27 November 1997).
\item \textsuperscript{235} Nattrass, Nicoli Mortal Combat: AIDS Denialism and the Struggle for Antiretrovirals in South Africa 2007 University of Natal Press, Scottsville.
\end{itemize}
upholding previous rulings that restrictions on the roll-out of ART for MTCT were unconstitutional, and ordering the government to ensure its general availability.237

This was a crucial victory for the right to access to healthcare, and towards solidifying the government's obligation to take active steps to realize that right for people with HIV. In Johnson's analysis, this decision had repercussions extending beyond merely access to ART, signalling “not only the consolidation of a human rights based response to AIDS, but also the shift from an emphasis on the civil rights of people living with HIV/AIDS to their socioeconomic rights. Indeed, within South Africa, this controversial social policy issue has been central in broadly defining the responsibilities of government to its citizens, and in attempting to operationalize the social and economic rights enshrined in the Constitution.238”

The next step was to advocate for the general provision of antiretrovirals for all who needed them. In February 2003, close to 15,000 people joined TAC's march on the South African parliament to demand a treatment plan.239 Yet even after the ANC Cabinet overruled Tshabalala-Msimang in 2003 to approve an operational plan for HIV, the Minister of Health resisted the implementation of the plan for years. International pressure began mounting as well, particularly following Tshabalala-Msimang's notorious appearance at the 2006 International AIDS Conference in Toronto, where her booth advocating the nutritional benefits of garlic, lemon juice, and olive oil against HIV was peaceably occupied by TAC supporters.241 However, only the eventual replacement of both Mbeki and Tshabalala-Msimang was sufficient to finally remove these two very difficult roadblocks to ART access; that Mbeki's successor Jacob Zuma, a man who notoriously told reporters how he had protected

himself from HIV by showering after intercourse, proved to be more progressive on HIV shows just how dire the situation had been.

By this time, however, the damage of denialism had been done. A demographic modelling study suggested that if ART had been rolled out nationally at the same rate as the Western Cape Province, which had bypassed the national government to implement its own ART program, 171,000 HIV infections and 343,000 deaths could have been prevented between 1999 and 2007. Nevertheless, although it came too late for so many people, the role of human rights, and of civil society and the judiciary in protecting those rights, had been cemented.

TAC’s actions had not gone unnoticed by the global community, particularly thanks to actions such as the high profile Global March for HIV/AIDS Treatment, targeting both pharmaceutical companies and the South African government at the World AIDS Conference in Durban in 2000. TAC’s actions, as well as the actions of countries like Brazil, whose government had overcome objections by the pharmaceutical industry to provide universal ART coverage in 1996, served to highlight the rights of those people most in need and least able to access ART. As in South Africa, the courts had been used effectively to enforce access to essential medicines in other countries, particularly in Latin America.

By late 2001, after lobbying by developing countries, the Doha Declaration on the TRIPS Agreement and Public Health specifically affirmed that the TRIPS Agreement “can and should be interpreted and implemented in a manner supportive of WTO Members' right to protect public health and, in particular, to promote access to medicines for all.” To ward off the exercise of some of the measures

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244 Hogerzeil, Hans V; Melanie Samson, Jaume Vidal Casanovas, Ladan Rahmani-Ocora, “Is access to essential medicines as part of the fulfilment of the right to health enforceable through the courts?” *The Lancet* 2006 Vol 368 pp.305–11.
245 More formally known as the Agreement on Trade-Related Aspects of Intellectual Property Rights.

It is worth noting that neither Brazil nor South Africa qualify for the most generous exemptions, as neither is classified as an LDC.
permitted under TRIPS, pharmaceutical companies in turn lowered their prices in developing countries.

Progress continued in 2003, when UNAIDS and the WHO jointly launched the 3 by 5 initiative with the goal of providing 3 million HIV-positive people living in low and middle income countries with ART by the end of 2005. Although the initiative eventually met less than half its target, former UN Special Envoy for HIV/AIDS in Africa Stephen Lewis speaks of it as a turning point in the discussion around universal access to ART. Thus, events in South Africa played an important part in expanding the human rights discourse around HIV beyond the civil and political rights of exceptionalism's initial incarnation to include some consideration of the socioeconomic right of access to healthcare; in this way, South Africa affirmed that a pro-rights HIV policy was not solely a Western import.

The Return of TB, and of Traditional Public Health

Although tuberculosis had never really gone away in many developing countries, it was only after nearly a decade of HIV that TB reappeared on the international health agenda, and it took a dramatic resurgence in the West to rekindle interest in the subject among policy makers and funding bodies. This key event was an outbreak of tuberculosis in New York City. In 1992, there were close to four thousand cases of TB in New York City; a city that held 3% of the nation's population accounted for nearly 15% of national TB cases. The aftermath rekindled the McKeown debate once more over whether the underlying problem was a lack of investment in TB programs, or a failure to address underlying social concerns such as poverty. Whatever their relative contributions, the TB budget had suffered drastic cutbacks over the previous two decades in the belief that TB was no longer a serious threat; in the end, the outbreak is estimated to have cost over one billion dollars to address, far more

than the cutbacks had saved\textsuperscript{251}.

Yet this outbreak did more than just highlight the importance of keeping TB programs in good repair. It showed that a neglected TB program could spawn a far more serious health risk: multi-drug resistant tuberculosis (MDR-TB). MDR-TB is more difficult to treat in all respects: treatment takes longer, costs more, requires more complex health infrastructure and expertise and is generally more unpleasant for the patient, all with a considerably lower chance of success. While rumours abound about the origins of HIV, there is no call for conspiracy theories when it comes to MDR-TB: it is an entirely man-made phenomenon. It arises not from the absence of TB programs, but from the existence of neglected, inadequate TB programs where treatment is incomplete or ineffective. It arises initially in patients who, for whatever reason, do not successfully complete a full course of treatment. In New York, not only did 44\% of patients who had previously been treated for TB show resistance to at least one drug, but more than 1/5 of patients who had never previously been treated for TB showed resistance to at least one drug as well\textsuperscript{252}. These latter patients did not have drug-resistant TB because they had received inadequate treatment in the past; they contracted it from someone else, demonstrating that once it develops, DR-TB can continue to spread to new patients.

At the time when HIV programs were globalizing human rights policies, the response to the resurgence of TB in New York adopted a far more traditional public health approach, which in turn was to prove influential elsewhere. First and foremost in the response was the re-assertion of the authority of the medical practitioner over the patient, primarily through directly-observed treatment in which patients take their medication under the supervision of a health worker to ensure that treatment is completed. A second crucial element is that considerable credit for the containment of the outbreak went to the use of long-dormant public health measures such as the detention of infectious patients,


\textsuperscript{252} Ibid. p.146.
reversing the trend away from hospitalization that had begun when drugs had first appeared. While similar measures had been rejected for HIV only a few years before, they seemed to gain wide acceptance for TB: Between 1989 and 1991, only 10 HIV-positive people were detained on public health grounds in the United States; by contrast, over 350 persons with TB were detained during the same timeframe\(^\text{253}\). On top of concerns about transmissibility, another reason such measures were implemented with little resistance may have been that many of those infected in the New York outbreak were homeless or otherwise marginalized; they were less organized, and less prepared to advocate on behalf of their rights than gay rights campaigners had been with HIV. Furthermore, they were unlikely to attract public attention or sympathy. In discussing a concurrent outbreak of MDR-TB in the New York prison system, Reichman notes that it was not until a prison guard died of the disease that the epidemic got any attention in the press: “Because of the tragic death of one white middle-aged man... more attention was paid to TB in just a few months than any of us had seen in our entire careers battling this disease\(^\text{254}\).” Whatever the underlying reasons, in the country where a rights-based approach to HIV had originated, the rights of the patient were much farther down the list of priorities when combating TB.

**Old Ideas, New Package**

The rekindled interest in TB spilled over into the developing world, where TB was on the rise in many places, as a result both of the emergence of HIV, and of the general neglect of TB programs. Even with reporting down, cases worldwide had increased throughout the 1980s, in part caused by the structural adjustment programs promoted by the IMF which had weakened national health systems. Such reforms have been directly linked to worsening tuberculosis outcomes\(^\text{255}\). In particular, managerial integration of


\(^{255}\) Stuckler, David; Lawrence P. King, Sanjay Basu “International Monetary Fund Programs and Tuberculosis Outcomes in Post-Communist Countries” *PloS Medicine* 2008 Vol.5(7) pp.1-12.
formerly separate TB programs led to deterioration of the quality of case finding and treatment\textsuperscript{256}. Although more recent than many of these restructurings, a withering analysis produced by the Stop TB Initiative offers similarly instructive insights into the collapse of the Zambian National Tuberculosis Program as part of an effort to reform and “generalize” the health-care sector, concluding that “the organizations which funded the reforms and the experts which advised the Ministry of Health... are as much or even more responsible for the TB control catastrophe which resulted from their engagement\textsuperscript{257}.”

By the time the WHO turned its attention back to TB in the late 1980s, the basis of their control policy (BCG vaccination at birth, along with case-finding and treatment prioritizing smear-positive infectious cases,) had not undergone any major policy changes in a quarter century\textsuperscript{258}. As a result of cuts, by 1989, the WHO Headquarters staff devoted to tuberculosis had shrunk to just two professionals\textsuperscript{259}. Now, however, a new approach was adopted and prioritized for global use. And while not developed with the New York outbreak in mind, aspects of it looked quite similar.

The product of the WHO's renewed attention to TB was the DOTS program. Although elements of the program had been in use previously at various times and in various places, DOTS was the first attempt at creating a standardized global program suitable for low-resource environments. It was based largely on the work of Karel Styblo\textsuperscript{260} in Tanzania. Recognizing that traditional TB treatment regimens, which could last 18 months or more, were proving to have low cure rates in low-resource countries\textsuperscript{261}, the first innovation was a new combination therapy that could be completed in a shorter period of time.

\textsuperscript{260} Styblo, Karel “Overview and Epidemiologic Assessment of the Current Global Tuberculosis Situation with an Emphasis on Control in Developing Countries” Reviews of Infectious Diseases Mar/Apr 1989 Vol. 11 Suppl. 2 pp.6-17.
\textsuperscript{261} As in the Kenyan example given earlier.
The second innovation was that patients would be supervised taking their medication through at least part of this shorter course of therapy. From these two innovations comes the original DOTS acronym: “Directly Observed Therapy, Short Course”.

Early analysis demonstrated that this process was not only effective in treating TB in low resource environments, but that it did so in a cost-effective manner. It was soon widely accepted to be among the most cost-effective health interventions available, comparable to measles immunization or oral rehydration therapy\(^\text{262}\) and certainly orders of magnitude more than ART. The end result was a program that, at least initially, was considered an unqualified success, and which relied heavily on a return to a more traditional paternalistic relationship between doctor and patient through the element of direct observation.

As with the exceptionalist approach to HIV, DOTS was quickly exported as a world-wide solution. In fact, the concerted attention paid to marketing DOTS made it even more of an explicitly one-size-fits-all solution than the rights-based approach to HIV had been. In 1993, the WHO hired an advocacy expert from the United States\(^\text{263}\). Within a few months, a major media event was held in which the WHO declared TB a “Global Emergency”. The WHO subsequently launched DOTS explicitly as a “brand” for their TB program\(^\text{264}\). In turn, selling a new program entailed finding buyers, even if buyers were less likely to be found in the low-resource environments for which the program was designed; as Ogden and colleagues argue, “The Global TB Programme explicitly intended to develop a policy package that was simple and marketable to policy makers and programme implementers... For advocacy, the targets were therefore policy makers in London, Washington and elsewhere in the industrialized world rather than in developing countries\(^\text{265}\).” This is not to say that the

\(^{262}\) Murray, C J; DeJonghe, E; Chum, H J; Nyangulu, D S; Salomao, A; Styblo, K “Cost Effectiveness of Chemotherapy for Pulmonary Tuberculosis in Three Sub-Saharan African Countries”, \textit{The Lancet}, 1991 Vol.338 Iss.8778 pp.1305-1308.


\(^{264}\) Ibid.

\(^{265}\) Ibid.
appropriateness of DOTS, like exceptionalism before it, was never questioned as a universal model\textsuperscript{266}. Nevertheless, criticism towards DOTS largely avoided the culture-clash rhetoric that had surrounded exceptionalism, and it expanded quickly. By 2007, more than 99\% of notified cases were reported to WHO as treated in DOTS programs\textsuperscript{267}. And given the World Bank's ranking of DOTS as one of the most cost-effective health interventions, “its 'recommendations' were taken very seriously in developing countries”\textsuperscript{268}. This branding of a policy, marketed to donors as a global solution, necessarily simplified the components to the point that it became difficult to carefully tailor programs appropriately for local circumstances\textsuperscript{269}. Overall, however, it succeeded in widely disseminating a program created primarily for developing nations and which was premised on a traditional public health approach to treatment.

In South Africa too, the introduction of DOTS was met with little fanfare. The shift to democracy had fewer implications for the treatment of TB than for HIV. This is despite the fact that while very few high profile South Africans have ever publicly admitted that they are HIV-positive, both Desmond Tutu and Nelson Mandela have spoken publicly about their experiences with TB; like many others, the latter contracted the disease during his imprisonment\textsuperscript{270}. However, TB policy was also not subject to the same obvious errors at the highest level; even the gaff-prone Tshabalala-Msimang managed only to say that it was important to "separate TB from HIV”\textsuperscript{271}. Instead, the response to TB, neglected in the black community under apartheid, gradually implemented approved methods. The

\textsuperscript{266} Lienhardt C & Ogden J. A. “Tuberculosis control in resource poor countries have we reached the limits of the universal paradigm?” \textit{Tropical Medicine and International Health} Jul. 2004, Vol.9 No.7 pp.833-841.


\textsuperscript{268} Kim, Jim Yong; Aaron Shakow, Kedar Mate, Chris Vanderwarker, Rajesh Gupta, Paul Farmer, “Limited good and limited vision: multidrug-resistant tuberculosis and global health policy” \textit{Social Science & Medicine} 2005 Vol. 61 pp.847–859.

\textsuperscript{269} Ogden, Jessica; Gill Walt, Louisiana Lush, “The politics of ‘branding’ in policy transfer: the case of DOTS for tuberculosis control” \textit{Social Science & Medicine} 2003 Vol. 57 pp.179–188.

\textsuperscript{270} Although this paper does not get into specifics, it must be acknowledged that prisons are an extremely high transmission environment for both TB and HIV.

Tuberculosis Register was introduced in 1995, making it possible for the first time to effectively track
cure rates and monitor control efforts; in 1996, tuberculosis was declared a top health priority by the
Department of Health, and the government committed to implementing a new control programme
based on DOTS. By late 2004, DOTS had been fully implemented, although the Province of
Mpumalanga was declared non-compliant in early 2005, leaving South Africa with 93% DOTS
coverage. Nevertheless, the TB burden continued to grow as a result of HIV/TB co-infection. And
the following year, XDR-TB hit the headlines.

The Resistance Movement: The Threat of DR-TB
Despite the prominent role of MDR-TB during the New York outbreak, the focus of the resurgent
interest in tuberculosis was on treating drug susceptible TB. Rising levels of MDR-TB in the former
Soviet Union, particularly within the prison population, did garner considerable attention, but it
remained largely overlooked in the developing world. One of the problems was that until 2000, with
the exception of high-income countries and former members of the Soviet bloc, few countries had
access to laboratories that could perform drug sensitivity testing reliably, few national tuberculosis
programs were managing drug-resistant TB, and even fewer were reporting reliable statistics. This
was particularly true in the WHO Africa Region, where barely 1/3 of all countries reported resistance
data, and only five did so between 2002 and 2007. As with HIV at the beginning of the African
epidemic, there were simply no data. Consequently, although the WHO declared TB in Africa to be
another emergency in 2005, partly as a consequence of HIV/TB co-infection, the WHO press release

\[273\] Ibid.
\[274\] For a detailed discussion of MDR-TB in the former USSR, see Reichman, Lee B., with Tanne, Janice Hopkins.
\[275\] Wright, Abigail, Matteo Zignol, Armand Van Deun, Dennis Falzon, Sabine Ruesch Gerdes, Knut Feldman, Sven Hoff
ner, Francis Drobniewski, Lucia Barrera, Dick van Soolingen, Fadila Boulabhal, C N Paramasivan, Kai Man Kam,
analysis of the Global Project on Anti-Tuberculosis Drug Resistance Surveillance” *The Lancet* 2009 Vol. 373 Iss. 9678,
pp. 1861 – 1873.
\[276\] Ibid.
makes no mention of drug-resistant TB whatsoever\textsuperscript{277}. And a 2003 overview of HIV/TB co-infection in Sub-Saharan Africa states optimistically: “Fortunately, in contrast to the situation in parts of the USA, HIV-related multi-drug-resistant TB has not yet emerged as a significant problem in Africa, for this would render TB once again an incurable disease\textsuperscript{278}.”

A Perfect Storm: Co-infection and Drug-resistance in South Africa

Yet in 2006, in the small town of Tugela Ferry in the South African province of KwaZulu-Natal (KZN), the first\textsuperscript{279} outbreak of Extensively Drug Resistant (XDR) TB was identified\textsuperscript{280}. All but one of the 53 patients died; median survival time from diagnosis was only 16 days. Of those patients that were tested for HIV, all were co-infected. Furthermore, resistance appeared to be a relatively recent phenomenon in the region: the majority of the XDR strains were from the KZN family of tuberculosis strains, which were first described in 1996 and at which time most were fully susceptible to first-line tuberculosis drugs\textsuperscript{281}. It was also highly probable that many of the infections had occurred nosocomially\textsuperscript{282}. Thus, all the concerns about the resurgence of TB appeared in a single package, and the outbreak generated alarmist headlines around the world\textsuperscript{283}. The response was drastic. And as in New York, the lessons learned about human rights from dealing with HIV did not seem to carry over.

Human rights have played little role in the response to TB in post-independence South Africa, before or after the emergence of XDR; the phrase “human rights” is not mentioned once in the NSP-TB

\begin{footnotes}
\item[279] First using the currently accepted definition of XDR. The term had in fact been used with a slightly different definition regarding a Latvian case earlier that year.
\item[281] Ibid.
\item[282] Ibid.
\end{footnotes}
2007-2011. By contrast, it appears nearly fifty times in the NSP-HIV 2007-2011, where “Human Rights and Access to Justice” is identified as one of four key priority areas\(^{284}\). That human rights were accorded a very different priority than in the HIV response is exemplified by the involuntary isolation\(^{285}\) of MDR and XDR patients in the aftermath of Tugela Ferry.

Some health practitioners were quick to support the isolation approach; in an article pointedly titled “XDR-TB in South Africa: No Time for Denial or Complacency”, Singh and colleague stated “Health workers and human rights advocates in South Africa and elsewhere must be reminded that although a country’s Bill of Rights may bestow a range of human rights on individuals, these rights can usually be restricted if doing so is reasonable and justifiable\(^{286}\).” The authors go on to specifically call for “[e]mulation of New York’s aforementioned successful approach in controlling its TB outbreak [which] could empower health officials in South Africa and elsewhere to act decisively in tackling emerging XDR-TB and MDR-TB outbreaks”. The article concludes that “While isolating such patients until they die—which in the case of the slightly less deadly MDR-TB could be years—has been described as ‘ethically questionable and impractical’, this option may, of necessity, need to be countenanced\(^{287}\).”

The judiciary, which had championed the Bill of Rights in the TAC cases discussed earlier, seemed to agree. In 2008, the High Court of South Africa upheld the detention of four XDR-TB patients at Brooklyn Chest Hospital until they were determined to be sputum-negative for three months\(^{288}\). This was but one example of the trend of courts siding with traditional public health measures in TB cases throughout the world. Going beyond the New York epidemic, the judgement in this case draws extensively from case law in other common law jurisdictions, particularly Canada,

\(^{284}\) South African National AIDS Council (SANAC), *HIV & AIDS and STI Strategic Plan for South Africa, 2007-2011*

\(^{285}\) Although, given the conditions discussed later “confinement” might be more apt than “isolation”.


\(^{287}\) Ibid.

\(^{288}\) *Minister of Health of the Province of the Western Cape v Goliath and Others* SA 248 (C) (28 July 2008).
whose Charter of Rights and Freedoms closely resembles the Bill of Rights. In one particularly influential case, the Ontario Court of Justice found that the solitary confinement of a TB patient, including periods of physical restraint, had been a justified violation of his Charter rights. The South African judgement relies heavily on this Canadian case in concluding that confinement is an acceptable infringement of human rights.

Such measures are, broadly speaking, in keeping with international law, under which it is generally accepted that governments may infringe on civil and political rights for public health purposes. Guidance on the limitations that may be placed on human rights in the context of public health may be found in the Siracusa Principles, which state: “Public health may be invoked as a ground for limiting certain rights in order to allow a State to take measures dealing with a serious threat to the health of the population or individual members of the population. These measures must be specifically aimed at preventing disease or injury or providing care for the sick and injured.” Thus, isolation of patients for public health purposes is permitted; however, the infringement on rights must be proportional to the public health benefits of that infringement. Under these criteria, drug-resistant tuberculosis may pose a sufficiently severe risk to public health that these measures are sometimes justified; this was also the conclusion of a legal briefing commissioned by the Medical Research Council.

However, these criteria were often not met in practice in South Africa. In cases like that described above, not only were patients having their right to liberty infringed, but they were having

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291 For a concise outline of the factors to be considered in this analysis, see Fidler, David. “SARS and International Law”, *ASIL Insights* Apr.2003.
other rights infringed in the process. This included not only violations of dignity and security due to sub-standard conditions in the places of detention, but effects beyond the walls of their confinement\textsuperscript{294}. For instance, forced isolated affected the individual's right to work. Furthermore, in such cases, particularly where the individual confined was the main breadwinner, isolation affected the rights of family members as well\textsuperscript{295}. Thus, both the civil and socioeconomic rights of the patient, and potentially the rights of third parties, were infringed upon, and their omission from the cost/benefit analysis is renders it insufficient. And although the fact the issue came to court demonstrates that those confined were able to exercise their right to due process, the wheels of justice turned too slowly; two of the four patients died before the judgement above was handed down\textsuperscript{296}. What is more, confinement was not used sparingly: at one point, approximately 1700 people, including children, were detained in TB isolation facilities, many of them in substandard conditions\textsuperscript{297}. In one instance, a patient was shot at Sizwe hospital in Johannesburg following protests about conditions for MDR and XDR patients\textsuperscript{298}. The practical result of these isolation measures is similar to that feared in the early days of HIV advocacy; the spectre of isolation and its accompanying hardships are discouraging people from seeking treatment\textsuperscript{299}. This has consequences not only for the patient but for others, as the disease remains in the community where it continues to spread.

A second crucial point is that not only are these infringements serious, they do very little to promote public health. In his detailed analysis of the issue, London notes that such measures will not be effective in preventing XDR transmission at the population level in South Africa. Most XDR and MDR patients in isolation were identified only by accident, as a result of treatment failure; given that much of

\begin{footnotes}
\item[295] Ibid.
\item[296] Minister of Health of the Province of the Western Cape v Goliath and Others SA 248 (C) (28 July 2008). 
\end{footnotes}
the burden of DR-TB remains undiagnosed, the effectiveness of isolation as a measure to protect against the spread of the disease in the community is minimal. This view is echoed by other authors.

In a response to the article by Singh and colleagues above, Andrews and colleagues declare:

One irony of this discussion is that patients diagnosed with drug-resistant TB in KwaZulu-Natal are being turned away from the referral hospitals where second-line therapy takes place. There is a waiting list of more than 70 patients for admission to King George V Hospital, where the majority of MDR-TB therapy is provided. Rather than keeping patients 'in'—the debate posed in this article—the reality is that health services are unable to accommodate the burden of MDR-TB patients seeking care.

Such shortages have also had disproportionate impacts on certain groups, raising further human rights concerns; a recent UNAIDS report notes “Resource constraints in particular have led to arbitrary and discriminatory detention, particularly in Southern Africa, often resulting in higher rates of detention for migrant and impoverished DR-TB patients.” Andrews and colleagues further note that isolation, as practised in the New York epidemic, was used in a very different manner. There it was intended to provide short inpatient stays and curative therapy; in most cases, the threat of detention was sufficient to ensure compliance with treatment that was available to all patients. In South Africa, the historical absence of effective treatment means that XDR-TB is usually fatal, and detention might continue until death. Thus, what worked in New York is not, in fact, appropriate for South Africa.

Not only do isolation measures not accomplish what they are intended to in South Africa, they would be unnecessary even if they did. Amon and colleagues ask “When should a tuberculosis program be able to invoke rights-limiting measures as a 'last resort' in order to protect the public good?” They conclude that, given the existence of less-restrictive, proven, and internationally accepted treatment approaches, isolation measures are not justified.
delivery alternatives, the choice between public health goals and human rights in the case of DR-TB is largely a false one. Indeed, they note, programs in Lesotho and elsewhere have demonstrated that community-based treatment models that respect rights can provide clinically effective and cost-effective care for DR-TB. Since the patients detained in South Africa are not generally refusing treatment and since other options, such as community-based treatment, offer a viable alternative to isolation, isolation is not necessary to achieve public health goals\(^{305}\). At the same time, without an international example of good practice to follow until recently, it is perhaps less surprising that South Africa has also largely ignored this issue. As Amon and colleagues note: “Although countries can be faulted for not widely embracing these alternative approaches, it should be noted that it was only in 2008 that a section on community-based treatment for drug-resistant TB was included in the WHO’s Guidelines for the Programmatic Management of Drug-Resistant Tuberculosis\(^{306}\).” Today, the WHO notes that “[a]lthough early in the history of [drug-resistant] TB treatment, strict hospitalization of patients was considered necessary, community-based care provided by trained lay and community health workers can achieve comparable results [to strict hospitalization] and, in theory, may result in decreased nosocomial spread of the disease\(^{307}\).”

Although the NSP is following suite, the broader issue of rights and TB is only slowly becoming a high profile one in South Africa. Where TB is concerned, only now is South Africa beginning to review the measures that it rejected nearly 20 years ago for HIV, and even then this does not appear to be a priority. Although underlying differences in transmissibility and treatment duration ensure isolation remains a more credible option than for HIV, the lack of discussion of these issues not only in the NSP but amongst stakeholders is concerning. Unfortunately, this general lack of focused

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\(^{306}\) Ibid.

interest on TB and rights, despite the magnitude of TB's effects, is mirrored in the rest of the world, and unlike with HIV, there is little evidence that any stakeholder in South Africa is going to assume a leading role as TAC did with HIV.

Chapter 5: Truths and Reconciliation
The current NSP evolved from the history recounted above to jointly address one disease where human rights has always been at the forefront of discussion, if not always of application, and another that a human rights approach seems to largely have passed by. In the past, this has led to some extreme contrasts; at one point, while HIV patients under a certain CD4 count could receive a disability grant denied to their equally poor but HIV-negative neighbours, a patient isolated for MDR TB would lose any social assistance grant during the period of their isolation. These considerable differences have not led to a proportionate discussion of how to reconcile them; the result, as outlined above, appears to be largely a set of HIV interventions with TB grafted on. Yet although the NSP lacks any explicit balancing of the two approaches, beneath the surface it is possible to see the influence these two approaches have on each other. Bringing these matters to the surface will serve to illustrate how integration may actually occur in practice, and some of the issues that may arise as a result.

Connecting the DOTS
The most obvious starting point is the scenario described early in this paper: We still have one patient with two diseases, and no explicit discussion of the best way to meet this patient's needs beyond the acknowledgement they should be addressed together. This scenario should come as no surprise in the context of the NSP, as it has been raised, if never resolved, in the past. Back in 2005, TAC reached the following conclusions:

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The contradiction between ARV and TB drug guidelines is unfounded. Both regimens require daily doses of multiple drugs and interruption can be life-threatening in either case yet those taking ARV often collect their drugs only once a month at the clinic and are entrusted to follow the treatment guidelines. For the many HIV-positive patients taking ARVs who must also undergo antiTB therapy, this DOTS paradox can be a source of aggravation and unnecessary burden. Similarly, a portion of patients perceive DOTS as mistrust in their ability to care for themselves and this may decrease the level of responsibility they take for selfcare.

As even the critics have acknowledged, HIV exceptionalism has helped to highlight human rights as a consideration in the context of health. Although the exceptionalist approach has in practice often remained exactly that, its influence has at times spilled over into other interventions. The current global standards for TB treatment have shifted towards a more “person-centred” model. However, on the assumption that a) TB treatment should be more person-centred; b) ART is currently person-centred; and c) TB and HIV treatment need to be coordinated for the sake of efficiency and efficacy, the immediate response might be to try apply the current ART approach to TB, just as TB has been inserted into HIV documents. To do so without further examination, however, would be unwise.

DOTS has long been a target of human rights activists, as the above quote from TAC suggests. Critics have raised concerns both that it stereotypes the patient as incapable of adhering, as seen earlier in the discussion around ART, and that it is not the least restrictive means for achieving a public health goal, as seen in the discussion around isolation. These arguments centre on the directly-observed treatment (DOT) aspect of DOTS. This aspect has become so synonymous with DOTS that a casual observer might think it was the central component, rather than only one element of a DOTS program. In a field so concerned with proper adherence to treatment plans, it would do well for all parties working with TB to renew their familiarity with all five elements of DOTS: a) political commitment with increased and sustained financing; b) case detection through quality-assured bacteriology; c)

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standardized treatment, with supervision and patient support; d) an effective drug supply and management system; e) a monitoring and evaluation system, and impact measurement. Few would question that most of these elements are, and will continue to be, crucial for both TB and HIV interventions, and as such appear in the NSP even if not under the guise of DOTS. The potential for flexibility in DOTS when these other aspects are highlighted has been identified by a number of authors as a way of improving TB programs\textsuperscript{312}. Consequently, to reject DOTS as a whole solely on the basis of one component of the program is unreasonable.

Nevertheless, it appears that this is what is happening, even if by omission rather than explicit rejection. Only upon closer inspection of the NSP does it become clear that although DOTS formed a central component of the response in the NSP-TB, the term DOTS does not appear once in the integrated NSP. This progression from the former NSP-TB stating that the “programme will continue with the implementation of DOT with standardized short course chemotherapy regimens as this has been proven to be the most appropriate way of ensuring adherence\textsuperscript{313}” to omitting any explicit reference to DOTS occurs without comment.

The obvious question to ask when considering scrapping an approach is whether it works. For DOTS as a worldwide program, the answer seems to be yes. Compared with a scenario in which pre-1995 TB trends continued, up to 6 million deaths are estimated to have been averted through scaling up DOTS\textsuperscript{314}. At the same time, aggressive marketing of the DOTS strategy by WHO as the sole solution to the global tuberculosis problem has undoubtedly contributed to pressure to prove that it works\textsuperscript{315}. Many of the predictions made for DOTS have not been realized. Indeed, from early on DOTS has been

\textsuperscript{313} NSP-TB 2007. p.22.
\textsuperscript{315} Cox, Helen S; Nathan Ford, John C Reede “Are we really that good at treating tuberculosis?” \textit{The Lancet} 2009 Vol.9 Iss.3 pp.138 -139.
criticized for not being as effective as claimed. A widely cited review\textsuperscript{316} suggesting that direct observation showed little or no advantage in curing tuberculosis over self-treatment at home included studies all over the world, suggesting the issue was not with application in any particular cultural context. A South African study included in this review found that treatment was actually more successful among self-supervised patients than among those under direct supervision\textsuperscript{317}. And the track record of DOTS in the African context did not prove it to be a one-size-fits-all model after all:

A typical “successful” national tuberculosis control programme in Southern Africa based on the DOTS (directly observed therapy, short-course) strategy has seen a three- or fourfold rise in the number of notified cases, over the past decade, with up to one-third of all new patients dying before the end of treatment. It is not surprising that communities and health care workers are sceptical of claims that DOTS is the “cure for all” promoted by the STOP-TB partnership as the theme for World TB day in 2001\textsuperscript{318}.

As the authors of the above go on to explain, however, the issue is not so much with what DOTS includes as what it does not: HIV. A widely circulated modelling study promoting DOTS which concluded that the “potential effect of chemotherapy (delivered as DOTS) on tuberculosis is greater in many developing countries now than it was in developed countries 50 years ago\textsuperscript{319}” was based on data collected in the Netherlands. As a result, HIV, as well as other differences in determinants of health in the developing world, were not included in the model.

DOTS is designed to treat TB and reduce transmission of TB. It has no impact on activation of latent TB, which is the main effect of HIV in a population. Furthermore, DOTS focuses on smear-positive TB which, as covered elsewhere, is less common in an environment with such a high degree of HIV co-infection. For the average clinician following international guidelines while working in such an


\textsuperscript{318} Godfrey-Faussett, Peter & Ayles, Helen. “Can we control tuberculosis in high HIV prevalence settings?” \textit{Tuberculosis} 2003 Vol.83, pp.68–76.

environment, co-infected individuals are likely to face a delay in diagnosis\textsuperscript{320}. Even a highly effective DOTS program, as originally envisioned, will have little impact on incidence of TB disease in a high-HIV environment without ART; high levels of ART coverage are needed to substantially reduce TB mortality in a high co-infection environment\textsuperscript{321}. Thus, the problem is not necessarily that DOTS is ineffective so much as it is that DOTS is insufficient where compounded by co-infection. Indeed, in those countries where HIV co-infection has not been as serious a problem, notably in Latin America, the promised effects of DOTS on transmission and incidence rates have materialized\textsuperscript{322}. Given that DOTS is an effective tool against TB, but not against HIV/TB co-infection, a better approach is to determine what needs to be done to retain the effective parts of DOTS and modify or replace the others necessary to find an effective solution.

From the perspective of many NSP stakeholders, the place to start in creating a more effective joint intervention is with directly observed treatment itself. In some cases in South Africa, TB adherence is demonstrably worse than ART, even though treatment for drug-sensitive TB lasts only a few months while ART lasts a lifetime\textsuperscript{323}. This was illustrated in a collaboration between TAC and Medecins Sans Frontieres to boost extremely low TB adherence in the Khayelitsha township of Cape Town, where a DOTS model was in place. TAC already had a very large presence in Khayelitsha, and ART adherence in the area was over 90\%\textsuperscript{324}. Furthermore, 68\% of TB patients in Khayelitsha were HIV-positive, and thus many of the same patients were involved in both programs. The resultant increase in TB drug adherence after TAC initiated the same model of treatment literacy and intensive

\begin{thebibliography}{99}
\bibitem{320} Hafkin, Jeffrey \& Victoria M. Gammino \& Joseph J. Amon “Drug-Resistant Tuberculosis in Sub-Saharan Africa”\textit{Current Infectious Disease Reports} 2010 Vol.12 pp. 36-45.
\bibitem{321} Atun, Rifat A; Lebcir, Reda M; Drobniewski, Francis; McKee, Martin; Coker, Richard J “High coverage with HAART is required to substantially reduce the number of deaths from tuberculosis: system dynamics simulation” \textit{International Journal of STD \& AIDS} 2007 Vol.18 Iss.4 pp.267-273.
\end{thebibliography}
support programs while applying the same approach to drug distribution as with ART suggested that patient autonomy and community education worked better than the DOTS model\textsuperscript{325}.

Such examples have been taken to suggest that a self-supervised ART model is superior, and should be swapped in for directly-observed treatment. There is some irony to this, as ART owes much to the TB treatment model. It was TB that demonstrated the necessity for combination treatment, followed by the need to simplify drug regimens to make combination therapy easier\textsuperscript{326}. The importance of reliable drug supply mechanisms, ensuring high quality at low prices, was also learned from experience with TB\textsuperscript{327}. Yet today Abdool-Karim and colleagues comment that “Paradoxically, longstanding tuberculosis services have lagged behind and could benefit from the incorporation of key lessons made from the scale-up of ART\textsuperscript{328}.” In this way the ART model is proposed as a superior option on the grounds that infringements on patient autonomy are the reason DOTS is less effective.

The South African study on the effectiveness of DOTS mentioned earlier is but one source drawing this same conclusion:

We think that surveillance of pill swallowing can be alienating and authoritarian. Surveillance can detract from the ability of the carer to provide support, can decrease responsibility for self-care, and can increase stress on the carer by transferring to him or her the responsibility for successful completion. By contrast, we speculate that the active part played by self-supervised patients in their own care may have encouraged staff to engage with them in a positive, supportive way\textsuperscript{329}.

While there may well be some truth to this, relying solely on this explanation overlooks other important factors. For instance, in the study above, cure rates were well below the WHO target of 85% whether or


not the patient underwent directly-observed therapy\textsuperscript{330}; this suggests other factors at play. At least one of these factors is poor implementation of the DOTS program. Without good implementation of the program, it is impossible to determine how much of the problem is with DOTS itself. This also highlights issues of measuring the quality of DOTS programs around the world; despite concerns that TB control programs may have incentives to overestimate treatment success\textsuperscript{331}, there have been no formal external evaluations of the validity of reported cure rates from national tuberculosis programmes\textsuperscript{332}. Thus, statistics may not reflect the true extent of implementation.

Poor implementation includes not only issues such as funding and infrastructure, including some of the explicit lessons from TB listed above, but the quality of interactions with healthcare workers. In the TAC example above, patients were suddenly dealing with an enthusiastic group running a well-resourced project. This alone may have had advantages over experiences with poorly resourced clinics with overworked staff. Indeed, there is evidence that it is the quality of the interaction with the healthcare provider, rather than solely the use of directly-observed therapy, that has the most influence\textsuperscript{333}.

Indeed, the current model in Khayelitsha promotes a supervision model for ART on a voluntary basis, where patients are able to choose their treatment observer\textsuperscript{334}, who can be someone other than a healthcare worker, such as a family member. Treatment literacy programs, as promoted by TAC for ART, can also help to inform the patient and ensure the relationship is a balanced one. The relationship in this case becomes more one of providing support than exerting medical authority. In recognition of the need to make DOTS more flexible in recognizing the needs of the patient, this model is now also

\textsuperscript{330} The highest level of treatment success in patients who had never been treated for TB before was 60%.

\textsuperscript{331} van der Werf, Marieke J & Martien W Borgdorff “Targets for tuberculosis control: how confident can we be about the data?” \textit{Bulletin of the World Health Organization} 2007 Vol.85 pp.370-376.

\textsuperscript{332} Cox, Helen S; Nathan Ford, John C Reede “Are we really that good at treating tuberculosis?” \textit{The Lancet} 2009 Vol.9 Iss.3 pp.138 -139

\textsuperscript{333} For instance, Volmink, Jimmy & Garner, Paul “Systematic Review of Randomised Controlled Trials of Strategies to Promote Adherence to Tuberculosis Treatment” \textit{British Medical Journal} Nov. 1997 Vol. 315, No. 7120 pp. 1403-1406.

recommended by the WHO\textsuperscript{335}. In this way, the benefits of observed therapy may still be gained while better respecting patient autonomy. Promoting positive relations between healthcare worker and patient lessens the burden on each. To see why this approach is preferable, one has only to think back to pre-DOTS TB programs, when patients had full autonomy, but no monitoring or support available when they failed to adhere\textsuperscript{336}; the failure of this approach is what led to DOTS in the first place.

There are further improvements that can be made to DOTS, with the added benefit of making the expansion and integration of ART more effective. For example, the much-lauded cost-effectiveness of DOTS ignored the costs to the patient, such as costs of transport and opportunity cost of missing work to attend therapy\textsuperscript{337}, factors which have lessened its effectiveness on the ground. Measures proposed in the NSP, such as ensuring that medical facilities are open outside of normal working hours\textsuperscript{338}, will help to address these concerns.

In the end, it seems clear that a rigid one-size-fits-all DOTS model is not the right solution to the TB/HIV epidemic. The TB intervention in the NSP could learn lessons from ART, as ART has from TB, but integration cannot assume they are completely interchangeable. Thus, the omission of DOTS from the NSP, whether intentional or incidental, should not remove commitments to those elements of DOTS still highly relevant to the NSP, even if directly observed treatment in its most formal incarnation is implicitly phased out.

**Resistance to Change and Changes to Resistance**

A second area where an HIV-based approach seems to have won out in the NSP is the promise of

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\textsuperscript{337} Although it should be noted that the omission of these factors was acknowledged in the original analysis: Murray, C J; De Jonghe, E; Chum, H J; Nyangulu, D S; Salomao, A; Styblo, K “Cost Effectiveness of Chemotherapy for Pulmonary Tuberculosis in Three Sub-Saharan African Countries”, *The Lancet*, 1991 Vol.338 Iss.8778 pp.1305-1308.

\textsuperscript{338} NSP, p.51.
universal treatment for all TB cases, including MDR and XDR, in addition to ART. Many of the same arguments were raised when advocating for universal access for DR-TB drugs as were used for ART; indeed, they were being made at the roughly same time. Ultimately, DR-TB treatment gained acceptance at the international level; between 1995 and 2002, the international TB community’s position evolved from one of non-treatment for MDR-TB in resource-limited settings to one in which numerous treatment programs had been approved for funding. WHO now advocates the DOTSPlus program for treating DR-TB. This outcome was influenced by the success of the higher profile struggle for ART, particularly given that “the argument that using second-line drugs for TB re-treatment will be too difficult will no longer hold sway; not when we can acknowledge that this will be easier than providing lifelong antiretroviral therapy in Sub-Saharan Africa.”

However, in the case of DR-TB, the issue of access to drugs is coloured by the all too apparent fact that DR-TB exists only as a result of failure to complete TB treatment, a problem captured in the maxim “Doctors who cannot treat tuberculosis properly should not treat tuberculosis at all.” Complex ethical issues around TB remain largely unexplored, particularly compared to HIV; one comparative literature search found 2998 entries for ethics and HIV, against only 179 for ethics and TB. If TB is indeed “arguably the most important neglected topic in bioethics,” then the issue that has been most overlooked is the balance between the rights of the individual and the community.

It is generally accepted that “a poorly functioning programme can create MDR-TB much faster than it can be treated, even if unlimited resources are available...The highest priority in stopping MDR-

339 NSP, p.44.
341 Ibid.
TB must therefore be its prevention." And just as a poorly functioning TB program creates MDR-TB, a poorly functioning MDR program leads to XDR-TB. In both cases, the result is increased levels of DR-TB in the community. According to one recent modelling study, if MDR tuberculosis case detection and treatment rates increase to the WHO target of 70%, without simultaneously increasing MDR tuberculosis cure rates, XDR tuberculosis could increase exponentially. In many countries, including South Africa, cure rates for MDR are considerably lower; thus, initiating MDR treatment without taking steps to ensure improved cure rates could make the problem worse. Complicating matters further, it is not entirely clear that even a well-functioning MDR treatment program will have a success rate meeting that threshold, given that available treatments for MDR are considerably less effective than for drug-sensitive TB and treatment for XDR is even less so. Taking a broad view of the population as a whole, there are thus sound reasons for only providing treatment for DR-TB once the program to treat drug-sensitive tuberculosis achieves a certain minimum standard.

At the level of the infected individual, however, such an approach is difficult to reconcile with that individual's human rights. In turn, the right to universal DR-TB treatment is in line not only with the Constitutional right to access to healthcare, but with the current WHO policy of universal access to DR-TB treatment. Consequently, although the rights of the community not to be infected are noted in the WHO's guidelines for ethical TB treatment, they exist within the context of universal treatment, not as a competing alternative. As a result, interventions under the NSP are limited to a framework where universal treatment must be accommodated.

At the same time, given the easily transmissible nature of TB, it may still be appropriate to


346 Blower, Sally; Virginie Supervie, “Predicting the future of XDR tuberculosis” The Lancet Infectious Diseases Jul. 2007 Vol 7 p.443.


permit treatment restrictions based on individual circumstances in order to protect the community, a factor which largely sets it apart from HIV. A legal opinion commissioned by the South African Medical Council suggested that termination of treatment is legally justifiable in some cases, including “Where, due to interruption and recommencement of treatment, there is an unacceptable risk that amplification of resistance will lead to strains of MDR-TB for which no treatment is available.” Even if this is the case, however, it raises the question of where and how to apply this standard, a matter of continued, if muted, international debate. One ethical challenge this raises is that “[W]hile denying treatment to unreliable patients may serve the aim of avoiding the promotion of drug resistance, a practice like this may be inappropriately discriminatory. Because the ability of health workers to make sound judgements about such matters is suspect, the extent and quality of institutional policy of patient exclusion needs to be explored.” As yet, this issue has attracted insufficient attention in South Africa, and the NSP offers no particular guidance on the matter.

This issue of balancing the needs of individual and the community also extends to the issue of prevention. In contrast to HIV, where new evidence promotes the idea of treatment-as-prevention, by which ART makes patients less infectious and thus treatment helps impact transmission, or drug-sensitive TB, where successful treatment also prevents new cases, current patterns of drug resistance may involve a more explicit conflict between resources. While DOTS is one of the most cost-effective health interventions available, the picture is far different for DR-TB. DOTS is based on precisely the two drugs to which all patients with MDR-TB are by definition resistant, and thus other drugs must be used. While a course of standard TB drugs costs roughly $20, MDR-TB drugs can cost $5000 or more.

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and XDR-TB treatment is far more expensive still\textsuperscript{352}. This does not include the additional costs of monitoring and treatment. The result is that “in countries where TB is endemic, resources spent curing a single case of MDR-TB could be used to treat 100 new TB patients\textsuperscript{353}.” Fortunately for South Africa, even though DR-TB is on the increase, it makes up a small minority of cases, and thus universal treatment of existing cases is not itself financially ruinous. However, it is still a considerable concern as only a limited pool of resources – both financial and technical – is available for TB. By one analysis, if initiation of DOTSPlus has even a minute impact on resources for DOTS, the net result is negative in terms of deaths, because the few lives saved by treating MDR are more than balanced by the lives lost from weakening services for drug-sensitive TB\textsuperscript{354}.

At the same time, however, there is evidence that treating MDR patients can be feasible and cost-effective in middle-income countries, provided a strong tuberculosis control programme is in place\textsuperscript{355}. The key, however, is that there must be a strong tuberculosis control program. Furthermore, as seen earlier, HIV poses an enormous burden on the effectiveness of TB programs. Thus, in South Africa, an effective response to DR-TB will not only require sufficient resources for DR-TB itself, but the support of strong, effective HIV and TB programs.

This issue of resources returns us to a further argument that was raised, and debunked, in the ART discussion: that Africans might in some way be less capable of proper drug adherence. Paul Farmer attacks this view that cultural differences may underlie differing adherence rates in his dissection of a South African anthropological study on the high default rate seen among Xhosa-

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speaking TB patients\textsuperscript{356}. Noting that it identifies several reasons, focusing on the “deep seated mystical beliefs” of those under study, while acknowledging others including side-effects of medication and “carelessness of certain patients” he observes that “nowhere was there any mention of the poverty of South African Blacks or of apartheid and its effects on the delivery of services\textsuperscript{357}.”

This challenges the traditional public health perspective which holds that “individual behaviour is implicitly assumed to be largely a matter of choice\textsuperscript{358}.” The truth, as outlined by Farmer, is that “throughout the world, those least likely to comply are those least able to comply\textsuperscript{359},” the result of what he describes as a “political economy of MDR-TB.” In situations like this, Farmer concludes, “It could be more easily argued that TB-control programs... have failed not through cultural insensitivity but rather through a lack of commitment to the destitute sick\textsuperscript{360}.” This lack of commitment includes assurances of adequate drug supplies, supply chains, and other issues over which the patient has no control. As discussed earlier, these are serious barriers to drug adherence and universal treatment for both HIV and TB. The good news is that these systemic issues are clearly something that can be addressed in tandem for both diseases, particularly as treatment itself becomes integrated. However, TB treatment will require monitoring to ensure that the best of intentions in treating DR-TB do not result in making the problem worse.

Two Toolboxes
Having established that everyone has a right to access both HIV and TB treatment, the NSP also overlooks a further crucial difference. The most immediate consequence of the historical neglect of TB as a public health priority is that there are fewer tools available in the toolbox, many of which are beginning to show their age in any case. A snapshot of the situation is provided by research funding

\textsuperscript{356} Farmer, Paul “Social Scientists and the New Tuberculosis” Social science & medicine 1997 Vol.44 Iss.3 pp.347 -358.
\textsuperscript{357} Ibid.
\textsuperscript{359} Farmer, Paul “Social Scientists and the New Tuberculosis” Social science & medicine 1997 Vol.44 Iss.3 pp.347 -358.
\textsuperscript{360} Ibid.
statistics from the National Institutes of Health in the United States. Estimated funding for TB research for the 2011 fiscal year was $189 million; while a considerable increase over even half a decade earlier, it lags far behind the more than three billion dollars spent on HIV research that same year. And it is barely double that still allocated to smallpox, a disease eradicated from nature in one of public health's greatest success stories\textsuperscript{361}.

Despite the desperate need for more effective treatments for DR-TB, no new class of drugs developed for TB has been put on the market since the 1960s\textsuperscript{362}. Furthermore, research has long been limited, as TB has not been seen as a profitable market; for instance, one promising clinical trial ended because the pharmaceutical company was concerned that if the drug were found to be effective for TB, it would be harder to market for more profitable conditions such as bronchitis in high income countries\textsuperscript{363}. Although TB research has made a resurgence in the past few years, with a number of new drugs, including two new classes of drug, in development\textsuperscript{364}, they are not yet approved for use.

Similarly, despite the urgent need, testing for drug-resistance remains complicated and time-consuming in most of the world. In South Africa, there are insufficient laboratory facilities: although in 2010, there were 7,386 laboratory confirmed MDR-TB cases and 741 confirmed cases of XDR-TB\textsuperscript{365}, the real results are undoubtedly far higher. Only recently have new diagnostic tools such as the GeneXpert been developed to provide both faster diagnosis of TB and better diagnosis of drug-resistance; while these are being rolled out in South Africa, they remain expensive and only available at certain locations. Compare this with the following account of HIV:

\textsuperscript{361} National Institutes of Health, Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC), March 2011. Online: \url{http://report.nih.gov/rcdc/categories/default.aspx} Accessed Dec. 2.2011
\textsuperscript{363} Reichman, Lee B. “How to ensure the continued resurgence of tuberculosis” \textit{The Lancet} 1996 Vol.347 pp.175-77.
\textsuperscript{365} NSP, p.24.
In the early years of the HIV/AIDS epidemic, some persons complained vocally that not enough was being done, that the responses of government, industry, and the scientific establishments were phlegmatic or indifferent. Quite to the contrary, the rapidity with which progress was made against HIV/AIDS is without precedent in the history of medicine. Within 2 years, the causative virus was identified; within 4 years, a blood test was available; within 6 years, drug treatment was being widely used\textsuperscript{366}.

Today, an HIV test can be performed in a low-resource environment without drawing blood, yielding results in twenty minutes; in contrast, the gold standard of TB diagnosis has remained unchanged for over 100 years. Thus, while many may lament the elusiveness of a cure for HIV, the resources made available have yielded nearly as much progress in thirty years as for TB in the entire modern scientific era. By 2009, there were more than 20 approved agents to treat HIV infection, from drug classes with seven different modes of activity\textsuperscript{367}. Even in the face of calls for pharmaceutical companies to drastically cut prices or permit generic licencing, new HIV drugs remain a potentially profitable proposition. And although the failure to discover an HIV vaccine remains a major disappointment, the only TB vaccine available, the BCG, dates from 1921, and has limited value beyond preventing tubercular meningitis in children.

As can be seen, research and development in TB lags far behind HIV, and risks falling even further behind if no steps are taken to remedy the problem. Thus, while research and development around both diseases should be a focus of the NSP, there needs to be recognition that there is a considerable imbalance in the tools available. To maximize the efficacy of a joint approach, this gap needs to be remedied.

Unfortunately, it appears the opposite is occurring; although the NSP explicitly calls for new TB drugs and diagnostics, including for DR-TB, the emphasis is often still on HIV, with little recognition of the comparative shortcomings in TB. For example, under Sub-Objective 2.5 (“Prepare


\textsuperscript{367} Food and Drug Administration (United States), “Antiretroviral drugs used in the treatment of HIV infection” Online: http://www.fda.gov/ForConsumers/ByAudience/ForPatientAdvocates/HIVandAIDSActivities/ucm118915.htm Accessed Dec. 15/2011.
for the potential implementation of future innovative, scientifically proven HIV, STI and TB prevention strategies”) only 1 of the 6 examples is for TB. While new innovations are doubtless vital for HIV as well, and the importance of rebuilding bridges between the government and the scientific community following the animosity of the Mbeki years should not be underestimated, the NSP misses the opportunity to acknowledge and address the existing gulf between tools available to address the two diseases.

Put to the Test
At the same time, while the NSP has drawn the TB response into a more human rights-based approach with little fanfare, there is even less acknowledgement of the NSP’s application of some of the more traditional public health measures more closely associated with TB to HIV. The most obvious is in the promotion of Provider-Initiated Counselling and Testing (PICT). One of the objectives under the new NSP is to “Maximize opportunities for testing and screening to ensure that everyone in South Africa is tested for HIV and screened for TB, at least annually.” The evolution of this objective can be seen when compared with the equivalent goal in the earlier NSP-HIV: “Whilst the NSP affirms that VCT remains the primary model, [it also] expands this model to include HIV testing that is offered by health providers to specified groups of people attending health facilities. It also proposes to identify new strategies for the provision of counselling and testing outside of health facilities.” Each of these are successive and substantial deviations from the VCT-only model initially propagated through exceptionalism; given the human rights emphasis that otherwise permeates the NSP, this deviation is deserving of more exploration.

It was an evaluation of consequences rather than intentions that led to the biggest modification to the original rights-based response. This shift could only have occurred as the understanding of HIV,

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368 NSP, p.46.
370 NSP-HIV, p.120.
and the ability to treat it, evolved. As discussed, exceptionalism originated in a climate where medical science seemed helpless. It was at this stage that voluntary testing and counselling arose as a pillar of the initial rights-based approach to HIV that placed the individual at the centre of testing decisions. By the time this model was exported from the West, it included high standards of consent before conducting an HIV test, paired with extensive counselling requirements for those being tested, ensured that nobody would be diagnosed without their consent, or lack assistance dealing with the implications of the test results. Soon, the VCT model was well entrenched in the African response as well. Indeed, the importance of voluntary testing, alongside extensive individual pre-test counselling, was confirmed by the South African courts\(^{371}\).

As knowledge about HIV increased, however, ideological conceptions of how rights should be protected in a public health response were challenged by another point of view that did not deny the importance of human rights, but questioned how they were implemented in practice. One of the key proponents of this shift was Kevin de Cock. Initially, he noted the problem in the UK, where an HIV-positive patient was never diagnosed despite frequent encounters with the health system\(^{372}\). However, it was in the context of the Sub-Saharan epidemic that the shortcomings of the exceptionalist testing model became most apparent.

A common argument had long been that the standard for testing was extremely resource-intensive, diverting healthcare workers, already in short supply in many African settings, from other work they could be doing. This was affecting healthcare provision as a whole. De Cock's approach went beyond this to suggest that although initiated to protect human rights, VCT standards now were having the opposite effect. According to De Cock, not only was treating HIV differently from other diseases actually increasing stigma around the disease, but the current testing system also meant

\(^{371}\) C v Minister of Correctional Services 1996 (4) SA 292 (T)

fewer people were getting tested, with implications for the epidemic. In an article returning to the exceptionalism discussion he had begun, Ronald Bayer describes part of the rationale behind changing testing procedures as follows:

Typically proponents of changing the human rights – informed regime on testing believed and asserted that an approach that assumed consent unless an individual declined would make it easier to say “yes”; that by making testing the default option individuals who might both for social reasons (fear of stigma and violence) and for psychological ones (fear of receiving a cruel diagnosis) fear opting in would be empowered to choose a course they indeed wanted to pursue. Less commonly articulated, but equally important, were assumptions about the extent to which the current context of the global HIV epidemic dictated the necessity of policies that would make it more difficult to say “no.” From that perspective it was in the interest of those with HIV infection to know their diagnosis because of the potential for their own clinical benefit. To such explicitly paternalistic reasons were added assumptions about how an increase in the number of people tested would increase the proportion of those with HIV who knew their status. That would, in turn, enhance the prospect of a behavioural change so central to the public health duty to interrupt the transmission of HIV.

Yet the factors outlined by Bayer underemphasize the one focused on by De Cock: Since diagnosis is a precondition for treatment, fewer tests mean that fewer people are eligible to receive treatment. Denying them life-saving treatment was the ultimate threat to their human rights. De Cock thus concluded that “Paradoxically, for many Africans, HIV/AIDS has become the main threat to the very notions that an approach based on individual rights aimed to protect.” He advocated an approach similar to that for other diseases, for which consent is implicitly assumed in a medical consultation and diagnosis is encouraged. He argued that this would have the additional benefit of normalizing HIV in the community, decreasing stigma that was heightened by the strict and complex procedures around HIV testing.

This issue of changing testing standards ignited debate at the highest levels of policy; in an unprecedented move, the UNAIDS reference group on the issue openly criticized the decision of

UNAIDS to loosen the restrictions on testing. In this case, the scenario of early debates between traditional public health and human rights advocates was almost reversed, as many human rights advocates found themselves defending the new status quo that had arisen as a result of exceptionalism. For some, it was difficult to come to grips with the fact an approach emphasizing human rights might be having the opposite effect from the one intended. One psychological analysis made of the situation suggests that after exceptionalism developed, “several well-recognized social psychological processes created inertia and resistance to change in positions adopted early in the epidemic and short-circuited feedback that might have resulted in more rapid normalization of public health practice and prevention research.” Edwin Cameron, himself an advocate in favour of expanded testing, noted that “responses from human rights protagonists have seemed to suggest an overly defensive posture, reacting with alarm to creative new models and suggestions, rather than engaging constructively with them in the light of the central and luminous fact that testing is the indispensable prerequisite to treatment and care, and thus that it embodies the difference between life and death.”

Soon, however, it was possible to point to a range of examples of similar approaches, and more importantly their effects. One of the first countries to switch away from the traditional counselling model was neighbouring Botswana, a country with even higher HIV prevalence than South Africa. Lesotho, completely landlocked by South Africa, soon followed. These countries were cited in favour of a change in South Africa's approach. Interestingly, so were countries where exceptionalist policies originated, including the United States, where a far less publicized shift meant that similar testing policies already applied to women attending antenatal clinics. Evidence from other countries was

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soon supported by studies showing that different testing models increased testing uptake in the South African context as well\textsuperscript{379}.

In the end, South Africa adopted a policy of PICT to encourage uptake of testing, further expanded in a 2010 national campaign to encourage people to get tested for both HIV and TB\textsuperscript{380}. South Africa's new policy of wider implementation of PICT has had repercussions for TB as well as for HIV; a 2011 study found that expansion of PICT for HIV in TB clinics drastically increased testing and subsequent access to antiretroviral treatment for patients with HIV-associated tuberculosis, supporting the efficacy of the new policy\textsuperscript{381}.

This example also illustrates the importance of evolving approaches to public health. This shift in testing policy was possible primarily due to the existence of effective treatment. In the absence of treatment, there may still have been public health advantages in terms of behaviour change among those who knew their status, but testing would have little tangible benefit for the individuals themselves. It is true that this shift was made before treatment was universally available, and that despite the goals of the NSP, it remains so today. However, there will always be a piece of the puzzle that is inserted last; one response to the new guidelines addressed this issue, suggesting that “No one wants a situation where people find out they’re HIV-positive and can’t get antiretroviral treatment. But if we waited until everything was perfectly aligned, we would never respond\textsuperscript{382}.”

In the end, just as privacy and autonomy were crucial when there was little a positive diagnosis could provide but a death sentence prefaced by a lifetime of stigma, the possibility of realizing an


effective right to healthcare seems reasonable grounds to reset the balance of rights. While, as Bayer states above, PICT may make it “harder to say no” to an HIV test, the benefits to the individual outweigh the potential harms; at the very least, the trade-off is better than that under the former approach that made it harder to say “yes”. In this case, a change that on the surface seemed anathema to many of the initial proponents of a rights-based approach proved beneficial to both the individual and the larger community. This points toward a way to shift from asserting the supremacy of one view of rights in the design of the intervention to prioritizing them in the consequences of that intervention.

Since this debate, a movement towards increased testing has been boosted by further gains in scientific knowledge, particularly the mounting evidence for the efficacy of treatment-as-prevention. One influential modelling study suggests that universal testing and ART, used in conjunction with other prevention methods, could eventually eliminate HIV transmission entirely\(^{383}\). Given the lack of discussion within the NSP, one might assume this latest evidence is partial motivation for another less publicized shift discussed below.

Alongside the increase in testing, contact tracing also plays a larger role in the NSP than it has previously: One of the specific NSP interventions is to “Improve HIV, STI and TB contact tracing to facilitate early diagnosis\(^{384}\)”. Contact tracing has long been a part of the approach to tuberculosis, although because it is resource-intensive it has not always been widely applied. Because of the implications for privacy and confidentiality, however, exceptionalism led to controversy in its application to HIV\(^{385}\). Now, some years after the testing debate, it appears as a key intervention in the NSP with very little discussion. Once again, given the potential benefits of identifying a patient early, both to themselves and the community, the balance has been tipped back towards this potential

\(^{383}\) Granich, Reuben M; Charles F Gilks, Christopher Dye, Kevin M De Cock, Brian G Williams Universal voluntary “HIV testing with immediate antiretroviral therapy as a strategy for elimination of HIV transmission: a mathematical model” *The Lancet* 2009 Vol. 373 pp.48–57

\(^{384}\) NSP, Intervention 3.1.3, p.48.

infringement paying sufficient dividends to be acceptable\textsuperscript{386}. Its potential benefits include not only helping diagnose and treat other infected individuals as early as possible, but identifying those not yet infected who may be at risk in order to assist with behaviour change. The NSP ultimately does not take this idea as far as it could; TAC’s proposal that sero-discordant couples be prioritized for ART was not included in the final draft. Nevertheless, the NSP seems to place sufficient value on this potentially rights-infringing approach that it appears with virtually no comment, the primary concession being a statement that “All health workers will be expected to facilitate contact screening for HIV, STIs and TB in a confidential and sensitive manner\textsuperscript{387}.”

Thus, it is possible to see how a rights-based approach can evolve to reflect new knowledge and resources. New evidence tempers exceptionalism, while awareness of human rights prevents over-reliance on excessively restrictive or authoritarian public health measures and medical interventions as has historically occurred with TB. As in the 1980s, a compromise between public health and human rights can be found once again. This time, however, it is not because there seemed no other option; rather, it can be justified on the far better grounds of “their joint commitment to lessening AIDS deaths and human suffering\textsuperscript{388}.” This approach seems perfectly suited to a reconciliation of the differing approaches to HIV and TB in the NSP and should be given due consideration as such when designing interventions.

**A Return to Context**

Having examined how the approaches to these diseases have affected the NSP’s creation, it is important to take a step back to look once again at the broader context of the NSP, as was done at the beginning of this paper. While many of the goals under the NSP are admirable, they also raise questions about

\textsuperscript{386} Armbruster, Benjamin; Stephane Helleringer, Linda Kalilani-Phiri, James Mkandawire, and Hans-Peter Kohler “Exploring the relative costs of contact tracing for increasing HIV case finding in sub-Saharan countries.” Journal of acquired immune deficiency syndromes 2011 Vol.58 iss.2 pp.e29 -36.

\textsuperscript{387} NSP, p.48.

their feasibility. For instance, universal testing on an annual basis will have significant costs, magnified by the additional costs of treating those patients identified. While that might be a sound investment if considered on its own, there will be tradeoffs. This increase comes at a time when other health priorities are also being considered; for instance, South Africa is once again debating universal health insurance\textsuperscript{389}. It also appears at a time when international donor funding is at risk; in November 2011, the Global Fund to Fight AIDS, Tuberculosis and Malaria announced that it will not be funding new grants for prevention and treatment until 2014, owing to “substantial budget challenges in some donor countries”\textsuperscript{390}. While this latter event affects the government of South Africa less than other countries, it has potentially serious ramifications for civil society in particular, and their ability to help enact the NSP. For interventions such as drug treatment that rely on predictable long-term funding, and otherwise risk making matters worse through development of drug resistance, this is a very serious consideration.

Funding also raises questions not only of what areas of health require the most attention, but what should be prioritized in South Africa beyond the health sector. As many people as are affected by HIV and TB, even more are affected by poverty and the underlying social factors that influence these two diseases. These other needs are also not being fully met; as the oft-repeated adage goes, even if the cure for HIV were a glass of clean water every day, it still would not be possible to cure everyone under the current system. Consequently, decisions must be made about how to balance all these competing needs even if they are all in aid of the same ultimate goal of population health. These decisions are not simple. For instance, it has been argued that general improvements in socioeconomic circumstances may have had more impact on tuberculosis worldwide over the last 20 years than specific tuberculosis programs\textsuperscript{391}. At the same time, people are sick with TB and HIV today, and require immediate care.

\textsuperscript{390} Wadman, Merideth “Wealthy nations have reduced contributions to global research and treatment programmes” Nature Dec. 2011 Vol. 480 pp.159-160.
\textsuperscript{391} Oxlade O, Schwartzman K, Behr MA, Benedetti, A; Pai, M; Heymann, J; Menzies, D. “Global tuberculosis trends: a reflection of changes in tuberculosis control or in population health?” International Journal of Tuberculosis and Lung
In considering the prioritization of different rights in the context of the NSP, it is appropriate to reconsider some of the voices heard in this discussion in order to see that the importance of broader social issues is ultimately widely agreed upon. Although Jonathan Mann appeared earlier as the person held most responsible for the globalization of HIV exceptionalism, that epitaph is misleading, as it fails to recognize the full scope of his views. Mann himself was an advocate of a much broader “new public health” that encompassed a much wider application of human rights principles. As he describes it, this new public health “recognizes that the positive impact of traditional public health work will be inherently limited and inadequate without a commitment to changing societal conditions which constrain health and create vulnerability to preventable disease, disability and premature death.” Thus for Mann, it would not be enough to address TB and HIV alone without broader societal change, and it is here that the traditional public health approach most needs to be challenged. As he puts it, “the framing of public health problems as 'dynamic diseases within a status quo society' leads public health professionals away from societal analysis, let alone confrontation” when quite the opposite is needed.

Another voice reaching a similar conclusion, albeit from a fundamentally flawed premise, is Thabo Mbeki, a man forever associated with poor HIV policy. In retrospect, however, his repeated assertion that drugs alone are not sufficient to address a condition that is the result of poverty and other socioeconomic factors holds considerable merit, although it unfortunately did little to stem the increase in disparity that occurred during his presidency. As Myer and colleagues suggest, the denialist underpinnings of Mbeki’s public statements extolling the socioeconomic causes of HIV in South Africa “may have led to an overshadowing in public health circles of societal factors as determinants of the spread of HIV/AIDS, leading many domestic researchers to focus on more proximal behavioral and biologic determinants of the epidemic.”

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393 Ibid.
394 Myer, Landon; Rodney I. Ehrlich, and Ezra S. Susser “Social Epidemiology in South Africa” Epidemiological Reviews
Fortunately, it appears that stakeholders in the new NSP have managed to separate the importance of this idea from the company it once kept; a strong thread of promoting socioeconomic rights runs through the NSP, though it is one that gets tangled up in the practicalities of the NSP identified above. The NSP explicitly positions itself within the government of South Africa's broader development agenda\(^{395}\), which seems an entirely sensible proposition. At the same time, the boundary between the NSP existing as a piece of that puzzle, and as a microcosm of the entire development agenda, is blurred. There was considerable debate in this regard during the drafting process, particularly around the extent to which broader societal interventions relating to poverty reduction and food security should be included explicitly in the NSP, and to what extent they should be linked only through the broader development framework\(^ {396}\).

In the event, the final draft opts for a very broad approach under the NSP. Given the importance attached to treatment adherence in this paper, it is appropriate to highlight one example designed to promote this goal. Sub-objective 1.8 (“Support efforts aimed at poverty alleviation and enhancing food security programmes”) states that “Poverty is one of the major contributors to poor health through food insecurity, which in turn is linked to HIV and TB acquisition and poor treatment adherence, so every effort must be made by government and its partners to ensure food security for all\(^{397}\).” While this is both an accurate statement and an admirable goal, it takes the NSP well beyond a response to HIV and TB, and burdens it with nebulous targets assigned across all Departments and Ministries.

Unfortunately, to paraphrase Stephen Lewis, if HIV and TB are everyone's problem, they become nobody's responsibility\(^ {398}\). Consequently, while drawing these connections is important, consideration must also be given to how best to realize them; a goal that is difficult to identify is going to be even

\(^{395}\) NSP, p.30.
\(^{397}\) NSP, p.37.
\(^{398}\) Lewis, p.170.
harder to achieve, particularly if there is nobody to take the lead in achieving it. Such consideration is not always evident under the NSP, and will have to be monitored by stakeholders throughout implementation.

Strangely, given this context, the final NSP changes course when it comes explicitly to addressing rights through law reform, asserting that “insofar as it seeks to play a central role in protecting human rights and promoting access to justice in the context of the response to HIV and TB, [the NSP] cannot address the sum total of all legal and human rights interventions required; instead, it is focused on a limited number of achievable, measurable and mutually reinforcing objectives and interventions.” At the same time, a series of specific recommendations for law reform that identified particular laws for review was removed in the published version, even though they would seem to have fit right into the narrow category of interventions outlined above; among them was the need to enact regulations under the National Health Act to ensure the humane treatment of isolated TB patients. For reasons unknown, this removal occurred after an ostensibly final draft had been circulated to stakeholders. The resulting human rights section is, ironically, weaker on human rights than the remainder of the NSP. This adds but one more reason to ensure that stakeholders maintain their interest in the NSP throughout not only its drafting but its implementation.

Chapter 6: Conclusion

The need to address HIV and TB through a coordinated response is not a new one; in his pioneering DOTS work, Karel Styblo recognized that “A substantial decrease in the risk of tuberculous infection in developing countries is essential because of the increase in number of AIDS patients with tuberculosis.” Yet it is only in the past few years that real steps have been taken to implement a joint response, and even now, as recognition of the need for a combined approach translates into action, the

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399 NSP, p.54.
400 Styblo, Karel “Overview and Epidemiologic Assessment of the Current Global Tuberculosis Situation with an Emphasis on Control in Developing Countries” Reviews of Infectious Diseases Mar/Apr 1989 Vol. 11 Suppl. 2 pp.6-17.
world is still falling behind targets for integration\textsuperscript{401}. In South Africa, which carries a greater burden of co-infection than any other country, effective integration is of paramount importance as it is now impossible to fully address one disease without also tackling the other.

The purpose of this paper is to draw attention to the underemphasis on TB in the response. An appreciation of the historical context of both diseases helps promote an understanding of why TB remains under-represented in the discourse on human rights and public health, and in turn the NSP; by situating the discussion in this context, it becomes easier to objectively assess potential TB interventions both for their efficacy and their implications for human rights. In this way, it should be easier to take advantage of the potential benefits of expanding the exceptionalist approach to bring attention to the ethical and human rights issues that are otherwise neglected in the TB context while not overlooking the unique characteristics of the disease that will impact how it can most effectively be addressed in the context of the co-epidemic.

Ultimately, the NSP is only one step towards implementing an effective response to HIV/TB co-infection in South Africa. As Abdool-Karim and colleagues commented on the previous NSP-HIV, “The publication of these comprehensive documents highlights that South Africa is not deficient in policy, but rather lacks either the will or the capacity to deliver\textsuperscript{402}.” Will and capacity in the implementation of the NSP are not solely the responsibility of government but of all stakeholders, and the under-representation of TB among these stakeholders is further reason to highlight its importance. This is particularly the case since TB stakeholders are not only fewer in number than HIV stakeholders but less diverse as well. As Zackie Achmat comments, “Although TB control has traditionally been based on great work by epidemiologists, clinicians and scientists, the active involvement of


communities has been limited or absent. This imbalance is particularly noticeable when it comes to human rights, which have been championed by civil society in the context of HIV, but remain largely ignored for TB. Schneider's assertion that “The fact that we have 'Aids activists' and not 'TB' or 'measles' activists is symbolic of the special political status of HIV” will remain unchallenged if TB's importance continues to go unrecognized.

A shift in attitudes is important, because action needs to be taken on TB, particularly in the human rights context. The existence of a right is not enough on its own, nor are education about that right or judicial confirmation of its existence: a right will ultimately only be realized if steps are taken to assert it. A cautionary tale is the case of Irene Grootboom, a South African who attempted to exercise her constitutional housing rights. The Constitutional Court found that the government had not met its obligations to provide adequate housing. It is still celebrated as a landmark victory for the advancement of socioeconomic rights. But when she died, eight years after the court's decision, Grootboom was still living in the same informal settlement.

Thus, while the NSP can point the response in the right direction, it is up to others to ensure the response follows that path. Where it is less successful, they can nudge it back on track. In the case of TB, this is all the more important because there are fewer people paying attention; stakeholders need to read between the lines of the NSP and recognize that TB is an inseparable component of the co-epidemic, rather than a lesser problem whose response conveniently coincides with that for HIV. As TAC concluded in their final review of the NSP: “Addressing HIV and TB under the same strategy is a crucial step for health care in South Africa. What is also crucial is that TB, and TB activists, not be

405 Government of the Republic of South Africa and Others v Grootboom and Others 2001 (1) SA 46 (CC).
silent partner in the relationship."
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