# Pills, Politics and Partners: NGOs and the Management of the HIV/AIDS Epidemic in the Eastern Cape, with special reference to the Lusikisiki Project, 2004-2014

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## Declaration

The work described herein was undertaken at the Fort Hare Institute of Social and Economic Research (FHISER), University of Fort Hare, under the supervision of Professor Leslie John Bank.

I hereby declare that this is an authentic record of my work and has not in its entirety or in part, previously formed the basis for the award of any degree of this or any other University. Wherever use is made of others' work, it is duly acknowledged in the text.

**Signature………………………                                    Date…………………………**

**Student: Fredrick Murambiwa Govere**

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**Supervisor: Professor Leslie John Bank**

**June 2014**

## Dedication

To my father and mother who have taught me perseverance and the fear of God and to my son Nathaniel Chikomborero Govere.

## Abstract


> "…ultimate hypocrisy" saying they were willing to put up hundreds of millions of dollars for infrastructure, but shied away from funding better salaries for nurses. She said Lesotho has just qualified for an "astronomical" 140 million dollar cash injection for health infrastructure. "Many of these clinics are very beautiful... unfortunately we don't need more empty beautiful clinics. Unfortunately the United States, like some other donors, will not put that funding into human resources – Anonymous MSF Lesotho employee."

South Africa is one of the few countries in sub-Saharan Africa where HIV prevalence rates remain stubbornly high.[1] This trend is both concerning and difficult to explain given that South Africa is economically well-resourced with a better health care infrastructure relative to other African countries.

The African National Congress identified the HIV/AIDS epidemic as a major public health threat to South Africa as early as the 1990s (Parikh and Whiteside, 2007; Gevisser, 2007). In response, international donors provided a substantial amount of financial resources to support improvements in South Africa's health care infrastructure. The persistently high rates of HIV/AIDS in the population beg for answers to questions such as why South Africa's political leadership has been unable to control the spread of the disease and what particular social, behavioural and economic factors have contributed to South Africa's disproportionate share of the global HIV/AIDS burden. At this point in time, public health experts still have not been able to definitively isolate the factors that explain the severity of the HIV/AIDS disease burden within South Africa's population.

While international donor aid continues to play a central role in the social, economic and health betterment in developing nations, its political impact on


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[1] *2006 Report on the Global AIDS Pandemic,* UNAIDS, 2006, <www.unaids.org/en/HIVdata/2006GlobalReport/default.asp> (accessed October, 26 2006).

local governance structures has been much debated.[2] In particular, the roles played by non-government organisations (NGOs) in the fight against HIV/AIDS in South Africa have been found to be complex, controversial, and their lasting value contested. Specifically debated is the disproportionate global investment in HIV/AIDS prevention, care and treatment in South Africa and the ways in which it has shaped intervention strategies, public and private policy, and the governance roles assumed by various national and local governmental agencies.

Despite the threat of diminished financial support from international donor agencies that has loomed heavily over recipient countries in recent years, a number of key international donors have actually scaled up their global response to HIV/AIDS, particularly in South Africa.[3] These donor agencies include the U.S. government's Presidential Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund, as well as non-profit humanitarian organisations such as Mèdecins Sans Frontiéres (MSF), commonly known as Doctors without Borders.

This study aims to critically examine the prevailing intervention strategy used by these international donors to "push the pill;" that is, to push a public health agenda that holds antiretroviral (ARV) therapy as the preeminent solution to fighting the HIV/AIDS epidemic at the expense of other intervention strategies.

[2] In 2006, it was estimated that 30-70 percent of all health care provision and education in Africa was provided by NGOs (Olivier et al 2006). Over the last decade an array of research has attempted to understand better the exact role of NGOs in health and health service provision and attempted to record and map such provision (Olivier et al, 2006; ARHAP, 2011).

[3] From 2009, total global funding for HIV /AIDS flattened; creating a potential funding gap; that is, the difference between the amount of money needed and the amount actually allocated. In 2011, there was a spending gap of 30 percent between the $16.8 billion allocated and the 2015 target of $22-24 million (UNAIDS 2012, "Global Report: UNAIDS Report on the Global AIDS Epidemic 2012"). By 2010 funding from donor agencies had dropped by 10 percent, thus raising concerns about the future of the international commitment to fight HIV/ AIDS globally. Although part of the decline was linked to exchange rate fluctuations, it was noted that there were deliberate decreases by some donors in the wake of the global economic crisis. Actual U.S. resources available in 2010 were $6.9 billion compared to $7.6 billion in 2009 (UNAIDS/The Henry J. Kaiser Foundation (2011, July) "Financing the response to AIDS in Low- and Middle-income Countries: International Assistance from the G8, European Commission and Other Donor Governments in 2010").

While a biomedical approach remains the most compelling intervention strategy, the fight against HIV/AIDS needs to be more comprehensive in its scope taking into account local knowledge and culture. This study will discuss how political rhetoric delivered through the media and monitoring, evaluation, and reporting systems has been used to embed a biomedical pill agenda into the organizational culture and intervention strategies implemented by local community-based organizations.

Through a process of strategic translation, HIV/AIDS has been portrayed as the number one health problem facing South Africa today; in fact, across all of Sub-Saharan Africa (World Health Organisation 2005a, 2005b). As such, the magnitude of the HIV/AIDS epidemic has justified the focus on making ARV drugs available throughout Sub-Saharan Africa at the expense of other interventions that could aim more precisely at the key social and health problems faced by the South African population which compromise health and well-being. The question about whose interests are donors and donor-funded agencies representing, and what are the intended and unintended consequences that result from these interests is the subject of this study. The study will attempt to shed light on these questions through a critical examination of the widely publicized HIV/AIDS intervention programme, the Lusikisiki Project, located in the Eastern Cape Province of South Africa.

I have drawn extensively from the development discourse literature and such scholars as Ferguson, 1990; Escobar, 1994 and 1995; Rist, 1997; and Mosse, 2005, to provide theoretical grounding for answering the questions posed.[4] The study will critically analyse the social and political factors that defined this reputedly successful HIV/AIDS intervention project. Further, the study will

[4] The development industry is often explained using a machine-analogy (Ferguson, 1990; see also Crewe and Harrison, 1998); that is, the development industry is the association of organisations and bureaus that spread the process of development internationally.

elucidate other cultural and behavioural factors that shaped the initiative in its battle against HIV/AIDS.

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## Acronyms and Abbreviations

| | |
|---|---|
| AIDS | Acquired Immune Deficiency Syndrome |
| ANC | African National Congress |
| ARVs | Antiretrovirals |
| COSATU | Congress of South African Trade Union |
| DFID | United Kingdom Department for International Development |
| DOH | Department of Health |
| ECAC | Eastern Cape AIDS Council |
| ECNGOC | Eastern Cape Non-Government Organisation Coalition |
| HAACO | HIV/AIDS Adherence Counsellors Organisation |
| HIV | Human Immuno-deficiency Virus |
| MSF | Mèdecins sans Frontiéres / Doctors without Borders |
| NAPLWHA | National Association of People Living with AIDS |
| NMF | Nelson Mandela Foundation |
| PEPFAR | President's Emergency Plan for AIDS Relief |
| PLWHAA | People Living With HIV/AIDS |
| PMTCT | Prevention of Mother-To-Child Transmission |
| SADC | Southern African Development Community |
| TAC | Treatment Action Campaign |
| TLP | Treatment Literacy Programme |
| UNAIDS | Joint United Nations Programme on HIV/AIDS |
| UNDP | United Nations Development Programme |
| UNICEF | United Nations International Children's Fund |
| UNIFEM | United Nations Development Fund for Women |
| UNFPA | United Nations Population Fund |
| USAID | United States Agency for International Development |
| WHO | World Health Organisation |

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## Chapter 1: Introduction and Research Overview

> A review of history shows that the controversy relating to HIV/AIDS was never about prevention, education and care, except when prevention involved drugs like Azidothymidine (AZT) and drugs for the prevention of mother-to-child transmission (PMTCT). The controversy was about treatment, drugs and the science of HIV/AIDS (Chikane, 2013).

Thirty-one years after the first diagnosed case of HIV/AIDS in South Africa, and despite variously tried interventions, the country's official HIV/AIDS policy has yet to produce convincing results (Parikh and Whiteside, 2007). This is despite the fact that South Africa has a much praised HIV/AIDS policy which is overseen by the South African National AIDS Council (SANAC) and co-chaired by the Deputy President and the Minister of Health[5] (Whiteside and Sunter, 2000; Furlong and Ball, 2005; Parikh and Whiteside, 2007).

While South Africa basks in the glow of a plethora of HIV/AIDS initiatives deemed successful in their implementation by a range of non-governmental organisations (NGOs), government agencies, private corporations, faith-based, and educational sector organizations, the overall response resembles shattered glass as opposed to a beautifully crafted stained-glass window. Furlong and Ball have noted that, "Despite nearly five million HIV-positive South Africans, the state responses to AIDS continues to be characterised by a gap between rhetoric and reality, lack of political will and tensions between state and civil society" (2005:128). One of the key problems they identify is that government is too reliant on external actors, primarily development agencies represented by the international NGO sector, resulting in a lack of integration and coordination of

[5] Furlong and Ball, *The More Things Change: AIDS and the State in South Africa, 1987 – 2003* (2005) and; Mary Crewe, *AIDS in South Africa: The myth and the reality* (Harmondsworth, England: Penguin, 1992). Each provides a critical analysis of pre- and post-1994 AIDS policies in South Africa.

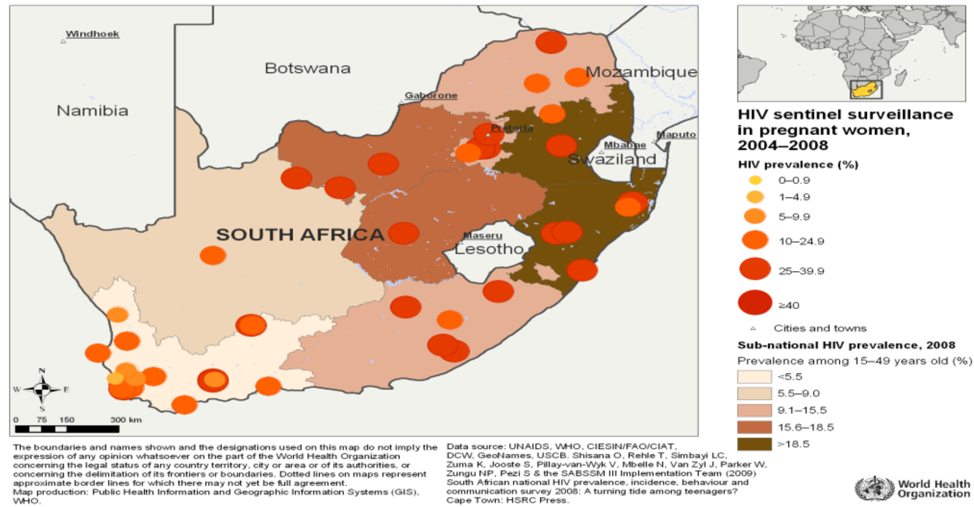
governmental policies in South Africa's HIV/AIDS prevention and treatment efforts.[6]

### 1.1 The HIV/AIDS epidemic in South Africa

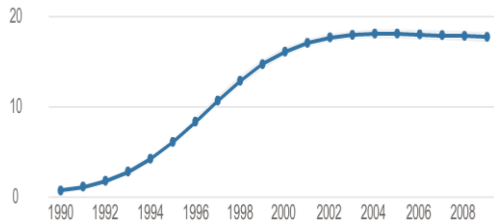
Below are graphic presentations of epidemiological factsheets produced by UNAIDS and the World Health Organization (WHO) between 1990 and 2008. These graphs depict HIV/AIDS prevalence and related issues in South Africa including antiretroviral (ARV) coverage. As with all data collection and reporting efforts, there are limitations in the accuracy of the data that are related to data collection techniques, reliability and consistency of data entry, and uniformity across data reporting sources. These limitations, in all likelihood, exist in the UNAIDS and WHO data as well but they are considered the best sources of cross-national HIV/AIDS data that exist today.

[6] Patterson (2005) also notes two consequences of reliance on external actors. First, the development of comprehensive HIV/AIDS policies is made more complex, because NGOs and donors are outside the control of the state and may challenge state policies. For example, within the South African context, Mèdecins sans Frontiéres (Doctors without Borders) began to import generic drugs for HIV/AIDS patients into South Africa despite state objections. While such actions were important for providing infected individuals with needed medicines, they do illustrate the lack of public-private coordination in HIV/AIDS programs and policies in South Africa. Second, because of the large amount of funding international donors provide for HIV/AIDS programs, they play a key role in designing HIV/AIDS programs and influence policy decision-making throughout Africa (Also see Patterson and Haven (2005), "*AIDS, Democracy and International Donors in Ghana*")

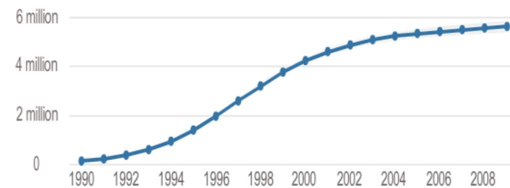
## 1.2 Epidemiological Factsheet: South Africa[7]



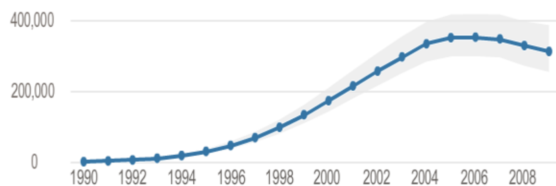

**Graph 1**
HIV prevalence in South Africa, Ages 15-49 yrs., 1990-2008 (%)



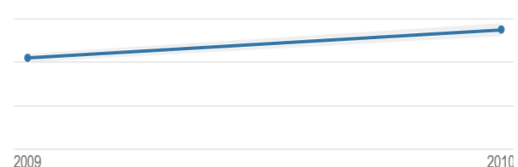

**Graph 2**
Number of people living with HIV in South Africa, 1990-2008




**Graph 3**
Annual number of AIDS deaths in South Africa, 1990-2008




**Graph 4**
ART coverage (%) in South Africa, 1990 2008 (CD4<350)




Public health researchers tracking trends in the prevalence of HIV/AIDS have found that South Africa consistently has a greater number of people living with

[7] Source: Map and Graphs 1-4: UNAIDS and WHO as quoted from Shisana, O. et al., (2008),

HIV/AIDS than any other country in absolute and relative numbers (Shishana, 2006; UNAIDS, 2004; UNAIDS and WHO, 2003). According to the latest 2010 prevalence rates release by South Africa's National Department of Health (NDOH), 30 percent of the population is now living with HIV/AIDS.

In spite of steady, albeit lacklustre, declines in HIV/AIDS prevalence rates since 2006, South Africa remains among a handful of countries globally that is hardest hit by the epidemic, with the fifth highest prevalence of HIV in the world. Likely accounting for the fact that South Africa receives more HIV/AIDS funding for treatment, care, prevention, and research than any other African nation.[8]

**1.3 Prevention versus treatment: Either/or?**

Public health advocates have long argued that "an ounce of prevention is worth a pound of cure." The prevention versus treatment dilemma posed by the HIV/AIDS epidemic is a complex one to untangle. Already infected populations have a certain death sentence without ARV therapy which allows them to live longer and enjoy a higher quality of life with each new generation of ARV drugs that come to market. This being acknowledged, when treatment investments significantly outweigh investments in prevention as is the current case, there is need for public discourse about best ways to rectify this imbalance. As New York University Professor, William Easterly, pointed out in 2006;

> "HIV/AIDS activists have been only too successful in focusing attention on treatment instead of prevention… If money spend on treatment went instead to effective prevention, between three and seventy-five new infections could be averted for every extra year of life given to an AIDS patient. Spending AIDS money on treatment rather than on prevention makes the crisis worse, not better" (Easterly, 2006).

There is general consensus that antiretroviral drugs alone will not stem the tide of HIV/AIDS in South Africa. Helen Epstein has pointed out that there [was] as yet

[8] See www.theglobalfund.org

little evidence [in 2003] that antiretroviral treatment programs run by governments automatically lead to reduced HIV infection rate on their own. She further noted that since the introduction of nearly universal access to ARV therapy in the US between 1996 and 1997, the annual number of new infections had still increased. Epstein continued;

> "The Botswana government has one of the most comprehensive government-run AIDS prevention programs in Africa, and it launched an HIV treatment program two year ago [then] that is a model for the rest of the world. Despite this extraordinary effort, the most recent survey shows the virus is still spreading at the same, staggering rate, so that Botswana has the highest infection rate of any country on earth." (Epstein, New York Review of Books, 17 July 2003).

While prevention efforts are key to turning around the devastation caused by the HIV/AIDS epidemic, from my personal experience working with more than 430 health care facilities in South Africa's two most rural provinces (Eastern Cape and KwaZulu-Natal), a major threat to HIV prevention efforts is the lack of knowledgeable and competent health care providers. Many of the facilities in these rural provinces are state-of-the-art in their construction, while at the same time many patients experience long queues to gain access to care. Much of the queuing has to do with a severe shortage of health care professionals, including doctors, nurses, and other direct patient care providers. Unfortunately, PEPFAR and many other international donors do not fund upstream health professions' training programs where the access bottleneck originates.

Herein lies a major component of the complexity of HIV/AIDS prevention and treatment policies. It is less a problem of lack of HIV/AIDS medical treatment and more a problem of the lack of skilled and competent health care practitioners, e.g., doctors, clinical associates, professional nurses, pharmacists, and social workers who can competently provide leadership in prevention and treatment efforts. Nattrass wrote in 2006 that, "failure to invest sufficiently in human resources – especially nurses – is likely to constrain any future increase in the

pace of the [treatment] rollout. Not only does this compromise the health and lives of thousands of people in South Africa – it also undermines the chances of achieving international targets to increase access to HAART"[9] (2006: 29).

### 1.4 Research Objectives

This thesis has four research objectives:[10] 1) to bring critical attention to how antiretroviral (ARV) therapy and its distribution in one South Africa community represents an HIV/AIDS intervention that was implemented at a significant cost to a more holistic approach to HIV/AIDS containment; 2) to critically examine the alliances that formed between a local NGO and an international-funded NGO, highlighting the intended and unintended consequences on a local rural community of their adherence to an externally-derived HIV/AIDS agenda; 3) to critically examine the ways in which the media and political rhetoric gave voice and influence to local ARV advocates and the effect this voice had on local governance and civic society; and 4) to discuss the role that an international NGO, using U.S. President Emergency Plan for AIDS Relief (PEPFAR) funding, played to promote the use of legitimate monitoring and evaluation reporting systems to ensure the acceptance of the "pill agenda" within a local community context.

Using ethnographic case study research methods, this thesis will demonstrate how a highly focused strategy to making ARV drugs widely available to infected members of the Lusikisiki community occurred at the expense of other holistic approaches to control the spread of HIV/AIDS. While ARV therapy is a critically important component of a comprehensive HIV/AIDS response, within the

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[9] According to Natrass (2006), South Africa's governmental initiative, Highly Active Antiretroviral Therapy (HAART), is largely supported by external funding, the largest being PEPFAR. (Also see Hassan and Bosch, 2006).

[10] The research objectives will be informed by a critical examination of the development and governance literature and illuminated by a case study of the Lusikisiki HIV/AIDS Project implemented in the Eastern Cape of South Africa. The case study tracks the activities of a local NGO, the Treatment Action Campaign (TAC) and its international ally Mèdecins Sans Frontiéres (MSF) and their joint interactions with the local Department of Health and the South African government

theoretical construct of development discourse, I will discuss the extent to which local stakeholders in Lusikisiki were constrained in their consideration of and discourse about whose plan and agenda was being implemented, the timing of this implementation, and what evidence existed to conclude that this approach was the most efficacious for their community.

The thesis assumes that the public and private response to the HIV/AIDS epidemic is a development issue. Further, the one-size-fits all approach in mitigating the spread and impact of the disease is not defensible public policy. Development theory scholars have argued that there is a level of subjectivity in the crafting of social and economic development policies that dissociates local history and customs in pursuit of the creation of an international development agenda that most often reflects the agenda of development experts as opposed to local experts.[11] This thesis seeks to critically examine the extent to which this has occurred in South Africa's governmental response to the HIV/AIDS crisis.

### 1.5 Theory informing practice

Gardner and Lewis argue that international development is "a construct rather than an objective state, a dream, perhaps, but one which many people assert has justified initiatives of continued Northern dominance over the South" (1996: 1). In *Encountering Development*, Escobar puts forward a similar argument, suggesting that, "development is a mechanism for the colonial and neo-colonial domination of the South by the North" (1995: 213). Because they each content that development is about domination, we are warned of the hegemony associated with top-down approaches to planning and implementing international development strategies, and that the consequences of such hegemony may have been underestimated. Similarly, Stirrat and Henkel (1997) argue that what can be viewed as orthodoxy, which assumes consistency and uniformity in practice, should rather be seen as an open arena for actively challenging the underlying

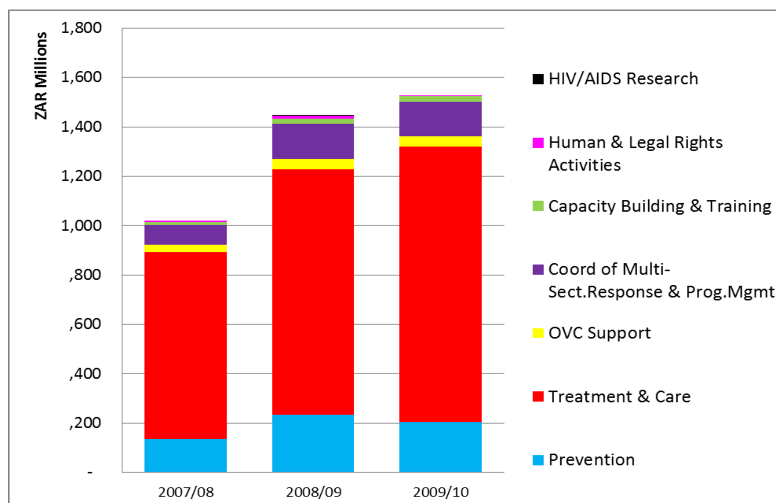
[11] See Ferguson, 1990; Escobar, 1995; Gardner and Lewis, 1996; Bond 2001; and Mosse, 2005.

assumptions of such strategies.[12] The principle assumptions of medical orthodoxy have been used to justify international HIV/AIDS development projects which focus almost exclusively on ARV treatment programmes. If one were to follow the admonitions of Stirrat and Henkel, this medical orthodoxy is amenable to challenge in its overarching relevancy in a South Africa context.

With a particular focus on the Eastern Cape, the graphs that follow illustrate how the funding of ARV therapy has by default allowed it to become the predominant strategy for mitigating the HIV/AIDS epidemic in the Eastern Cape.

## 1.6 Eastern Cape HIV/AIDS Spending[13]

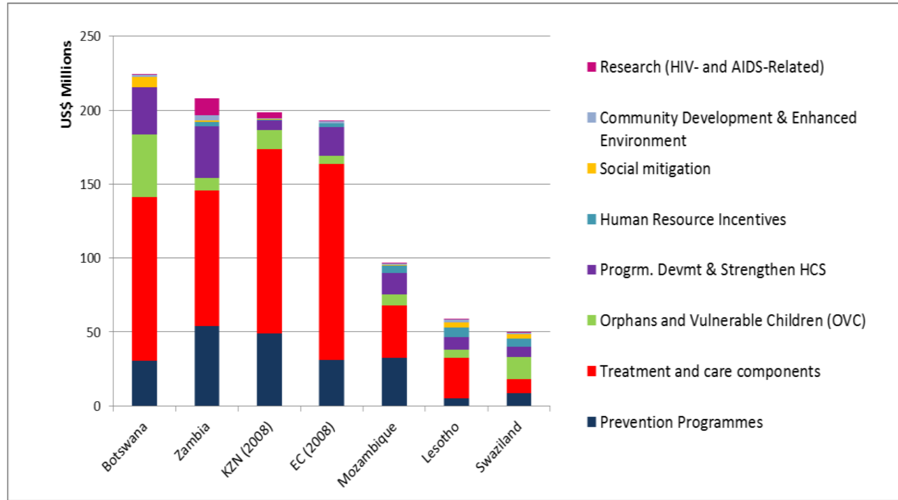
**Graph 5**: Total HIV/AIDS Spending in the Eastern Cape Province, 2007-2010



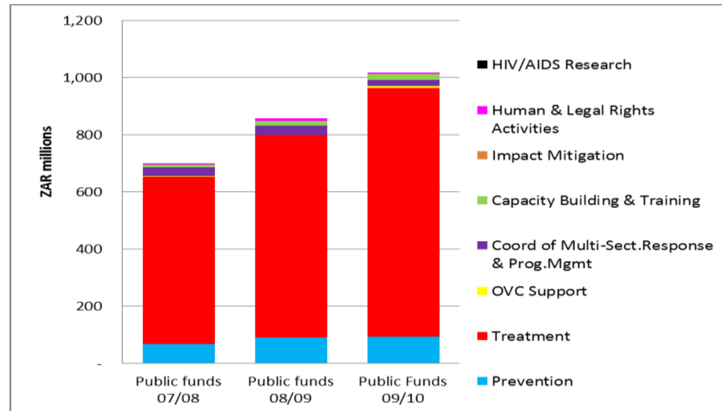

[12] The one-size-fits all approach in the fights against HIV/AIDS which is based on a biomedical approach can be seen as an example of such orthodoxy.

[13] Source: Graphs 5-9: I am indebted from the Eastern Cape HIV Donor Spending Summit, 24th-25th February 2011, East London, organised by the Eastern Cape AIDS Council (ECAC).

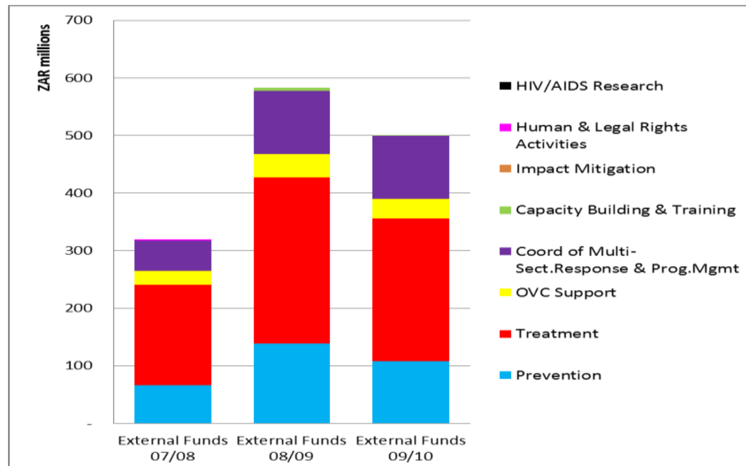
**Graph 6**: Comparison of Spending Priorities by Southern African Development Community (SADC) in the Eastern Cape



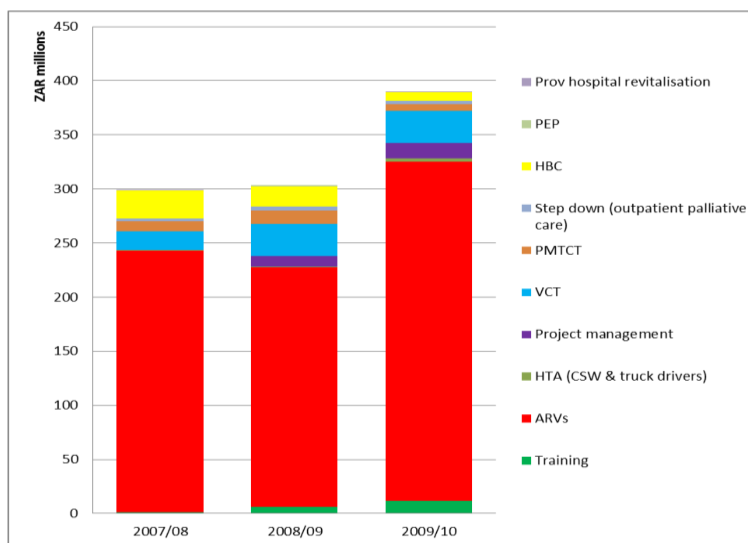

**Graph 7**: Public spending on HIV/AIDS, Eastern Cape Province, 2007-2010




**Graph 8**: Externally-funded HIV/AIDS activities, Eastern Cape Province, 2007-2010



**Graph 9**: Department of Health spending by activity, Eastern Cape Province, 2007-2010




## 1.7 Problem Statement, Aim, and Objectives

While an outsider view of the Lusikisiki story has been told numerous times, the aim of this study is to present an alternative critical view as an AIDS activist who has played an insider-outsider role. The story I tell focuses on the political rhetoric and social media dynamics that were at play in the reporting of the successes of the Lusikisiki HIV/AIDS Project. This focus is informed by the interactions and power dynamics that existed between local and international NGOs, governmental agencies, and the international donor agency that funded the project.

It is well understood that donor assistance comes with conditions and outcome expectations. Often the power imbalance between donors and recipients results in NGOs modifying their internal program mission and focus to meet the expectations of an external donor (Edwards and Hulme, 1998). Degnbol-Martinussen and Engberg-Pedersen have argued that donors impose their own norms, values, and priorities on their funding decisions and that these priorities often reflect development strategies that are currently popular (2003).

In this study I have specifically focused on the interactions and power dynamics between a local and international NGO and the funding agency and how the resulting synergies shaped the widely publicised successful story on the Lusikisiki HIV/AIDS Project.

The international NGO*,* Mèdecins Sans Frontiéres (MSF), commonly known as Doctors without Borders, with funding from the PEPFAR coordinating with a local NGO, the Treatment Action Campaign (TAC), are the key actors in this story. The value of the current analysis is that it brings to light how one community, and its reportedly successful HIV/AIDS project, shaped broader public policy decisions on a countrywide basis. Further, it questions the politics and coercive dimensions of this project with regard to the local community it was designed to serve, suggesting that the "success" of Lusikisiki should have been carefully scrutinized before its wider replication to other rural communities in South Africa was implemented.

The research questions of this study relate to the political dynamics and strategic decisions made in implementing the Lusikisiki HIV/AIDS Project. Specifically, they explore the political rhetoric and media campaign used by the Treatment Action Campaign (TAC) as influenced by its international ally, MSF and how together the campaign resulted in the Lusikisiki HIV/AIDS Project being christened a model of best practice. This Lusikisiki case study is a vehicle for examining the strategies employed by a local and international NGO, with funding from an international donor, to co-opt local and state governance structures into accepting an externally-imposed development agenda.

Specific research questions include:

1) What political and governance factors characterised the NGO-funding agency collaboration in the Lusikisiki HIV/AIDS Project?

2) What were the strategic dynamics and tactical decisions that underpinned the collaborative actions of the TAC, MSF, and PEPFAR funding in the Lusikisiki Project?
3) What were the key strategic decisions used by the TAC and MSF to deem the Lusikisiki HIV/AIDS Project a success?
4) Did the planning and timing of the Lusikisiki HIV/AIDS Project reflect community needs as expressed by local stakeholders?
5) What role did the monitoring, evaluation, and reporting system function play in legitimizing "the pill agenda" deployed in the Lusikisiki HIV/AIDS Project?

## 1.8 Research Design and Methodology

A mix of qualitative methods was employed in conducting the fieldwork for this study. The use of qualitative research method (key informant interviews and participant observation) allowed for relationships between actors and environmental influences to be more fully explored. As Walker notes, "reaching parts other techniques do not" (Walker, 1985: 18) by allowing the researcher to "see through the eyes of" others (Bryman, 1988: 76). Qualitative methods ensure a more in-depth vision of events, while the ethnographic approach provides not only depth of vision but also provides the 'fragrance' of events being studied (Eisner, 2004).

### 1.8.1 An Actor-oriented Approach

Increasingly actor analysis is being used to study the role of international donors, research organisations and non-governmental organisations (NGOs). In the same way, the framework allows an analysis of actors at the village and state levels. This analytic approach principally maps relationships and the flow of information between actors to provide a basis for reflection and action (Biggs and Matsaert, 2004). The precursors to actor analysis include anthropological and social network research techniques.[14]

[14] See: Long and Long, 1992; Long and Van der Ploeg, 1989; Lewis, 1998.

An actor-oriented approach and its analytic tools are all about human relationships and can therefore be considered a political analysis. This approach requires sensitivity and awareness with an acknowledgement that the user is never neutral. An actor-oriented approach can reveal information that some actors may not find easy to accept. It is important to acknowledge that different actors may have different interpretations of reality and that these interpretations may be politically motivated. Actor timelines help to reveal differing orientations and perceptions of reality. The actor approach to analysis has enabled topics that used to be seen as academic study of political economies to be practically applied within the broader framework of development theory (Biggs and Matsaert, 2004).

## 1.9 Data Collection Methods

### 1.9.1 Interviews

An interview is a method of data collection that may be described as an interaction between an interviewer and interviewee for the purpose of obtaining perceptually valid and personally reliable information. Interviews may range from casual conversation and brief questioning to more formal, lengthy interactions (Marshall and Rossman, 1995: 82). Fontana and Frey (1994) note that there are a number of interviewing models that can be applied in a qualitative-oriented research study. In general, there is the formal and informal interview. The choice depends largely on the aim of the study and researcher preference. Formal interviews are generally employed in structured settings in order to standardise topics and questions. Hammersley and Atkinson (1998) and Marshall and Rossman (1995) suggest that in-depth interviewing is most suitable for a qualitative case study. Described as a “conversation with a purpose,’ in-depth interviews are intended to elicit a participant perspective and enhance the understanding of a social phenomenon of interest.

This study employed three main types of interviewing:

- *Semi-structured formal interviews* - These interviews were always pre-arranged by a formal exchange of letters or emails and were held at an agreed upon time and place. These interviews used a detailed interview plan, although I also tried to maintain some flexibility so that I could be modified as needed and when necessary. Where consent was given, formal interviews were recorded and subsequently transcribed for thematic analysis. Where consent for recording was withheld, notes were taken and recorded in a field journal during the interviews.
- *Minimally-structured formal interviews* - These interviews were similar in structure and format to the semi-structured interviews, but I used an interview framework rather than a detailed interview plan to allow greater flexibility in the line of questioning.
- *Informal conversations* - As the name suggests, these were informal conversations held on an as needed basis when an opportunity arose. Notes were either made at the time when possible and practical or at a subsequent time in a field journal.

### 1.9.2 Participant observation

The concept of participant observation entails that of an observer of human interactions in a natural setting where the observer also participates in some fashion in the interactions of those being observed (Blumer, 1969: 39). Participant observation represents the delicate balance between subjectivity and objectivity as the participating observer is also a subject of the observed. The researcher's personal experiences and values, especially those involving empathy, are recognised as integral to the research process but are constrained by the accepted standards of observation that include 'objective' distance (Clifford and Marcus, 1986).

I was an active participant in many phases of my research, either as scribe in workshops and meetings, or as a research representative or participant in a number of multi-stakeholder partnership meetings and workshops. Simply through my involvement in the everyday activities of the partners involved, I

became a de facto participant observer. The roles I played in the Lusikisiki Project gave me a unique opportunity to observe donor, NGO, and government officer behaviour. Clifford and Marcus (1986) warn that participant observation can be the least objective of all data collection methods, and therefore it relies most heavily on the integrity and intellectual honesty of the researcher, whose personal experiences cannot be replicated by the very nature of the research method.

### 1.9.3 Document Review

Documents collected and reviewed for this study include:

- Relevant sections of official government documents, such as the national health and HIV/AIDS policy documents, partnership agreements, archived files
- Donor documents and policies related to the Lusikisiki Project
- Internal reports and correspondence related to the Lusikisiki Project
- Lusikisiki Project partnership progress reports and evaluations
- Journal articles covering partnership involved in the Lusikisiki Project
- National and local newspaper coverage of the Lusikisiki Project

### 1.9.4 Data Collection Sites

The sum of data collected, using ethnographic research techniques, included secondary documentary review; in-depth interviews; and participant observation of the daily activities and interactions of project NGOs with other relevant actors.

Between August 2007 and March 2012, one-on-one interviews were conducted with key stakeholders in the Lusikisiki HIV/AIDS Project which included community members and Department of Health staff, e.g., nursing staff and community health workers, who performed the everyday clinical work in the clinics and hospitals surrounding Lusikisiki, as well as in the East London District Health Office. Specifically, these interviews were conducted with Mèdecins sans Frontiéres staff, members of the HIV/AIDS Adherence Counsellors Organisation

(HAACO), the Department of Health, clinical staff in the local community clinics and district hospitals, members of the Treatment Action Campaign staff, and governmental officials.

My fieldwork lead me to become more directly involved as a participant observer in Lusikisiki project activities by attending seminars, conferences, and workshops organised by project staff and other key stakeholders. This engagement deepened my understanding of how the programme and cooperative partnerships worked in practise.

Department of Health staff at a local, district and provincial levels were interviewed together with other state agency staff that had different roles and responsibilities in the project. The TAC staff and volunteers were interviewed at the local district level as well as the provincial level. Attempts were made to conduct interviews with the national TAC office as well as the Nelson Mandela Foundation. MSF staff was interviewed in Lusikisiki prior to their departure in October 2006. HAACO staff members in Lusikisiki were also interviewed. I randomly selected three clinics in the Lusikisiki area: one centrally located; one within reasonable distance to town; and one rural clinic with referral relationships to two rural hospitals. To ensure the face validity and triangulate the data collected from these clinics, I interviewed nurses, adherence counsellors, and lay counsellors as each represented a different role with patients and the power quotient was different for each as a result.

Contacts established during my preliminary fieldwork in Lusikisiki in August 2006 provided an entry point for subsequent interviews. Documents reviewed were obtained from four organizations working closely with the DOH on the Lusikisiki Project. These organizations included: the Eastern Cape AIDS Council (ECAC), Eastern Cape Socio-Economic Consultative Council (ECSECC), Centre for AIDS Development, Research and Evaluation (CADRE), and the Eastern Cape NGO Coalition (ECNGOC). Despite a successful visit to the TAC national office in

Cape Town, I was unsuccessful in my attempt to interview Zackie Achmat, the founder and Chairperson of the TAC.

Finally, my experience working as an HIV/AIDS Monitoring and Evaluation Officer, Programme Project Coordinator, and Monitoring and Evaluation Advisor of HIV/AIDS programmes in the Eastern Cape (an NGO position funded by PEPFAR, the Centres for Disease Control (CDC), and the Global Fund) have enriched and informed the findings of the case study because of the first-hand, on-the-ground experience in HIV/AIDS programme operations that I bring to the current research effort.

### 1.9 The Lusikisiki HIV/AIDS Programme as Case Study

Map of South Africa locating the case study community of Lusikisiki

Source: MSF and NMF, 2006: 6

Lusikisiki is situated in the Eastern Cape Province of South Africa. It is one of the most penurious and rural areas in the country which is characterized by an under-resourced public health sector. Located in the former homeland of Transkei, Lusikisiki was a recruiting reservoir for migrant labour to the mines which has significantly affected family structures and contributed to the high level of HIV-infections. It is estimated that about 24 percent of the adult population (15-49 years) in Lusikisiki are HIV-infected (Walker et al., 2004; Mèdecins sans

Frontiéres et al., 2006; Steinburg, 2008). While other areas in South Africa have been harder hit by the HIV/AIDS epidemic than Lusikisiki, the epidemic remains the single gravest public health catastrophe Lusikisiki has experienced in living memory. The rate of HIV prevalence among pregnant women is estimated to be about 30 percent.

In early 2003, the same year that the world's largest HIV/AIDS donor fund, PEPFAR was established, an international humanitarian NGO, Mèdecins sans Frontiéres joined with the Nelson Mandela Foundation (NMF) to launch the HIV/AIDS programme in Lusikisiki in partnership with the Eastern Cape Department of Health. The programme was distinctive because treatment was delivered through community-based public health clinics, not hospitals, and services were provided by nurses, not doctors. The principles underpinning the programme were that in the context of an epidemic as pervasive as this one, with chronic shortages of medical personnel, access to treatment would only be successful if it was decentralised with the clinical tasks delegated to professional nurses supported by lay community health workers. According to COSATU[15] "…hospitals cannot bear the burden of HIV/AIDS unless treatment is decentralized to primary health clinics." Because Lusikisiki was an isolated rural area with a dispersed population and little access to hospitals, the programme design was to decentralise treatment access to the clinic level under the management of trained professional nurses (2006: 34).

When MSF launched the programme in 2003, about 60 percent of nursing posts in the Lusikisiki community's 12 clinics were vacant (Mèdecins sans Frontiéres et al., 2006); drug supplies were erratic; and most of the medicines listed on South Africa's Essential Drugs List had never made their way to the Lusikisiki clinics (Mèdecins sans Frontiéres et al., 2006); only one of the 12 clinics had electricity, one had running water, and none had a working telephone or fax machine. Within three years, 46, 000 HIV tests had been performed in Lusikisiki and 2, 200

[15] COSATU stands for Congress of South African Trade Union.

people had begun antiretroviral therapy (Mèdecins sans Frontiéres et al., 2006). About 100 people per month were being initiated on an ARV therapeutic regimen, which meant that the rate of treatment had begun to match the rate of diagnosis of HIV infection. It was an extraordinary launch, but also a precarious one as questions about the programme's sustainability in Lusikisiki arose.

When antiretrovirals (ARV drugs) were introduced in 1996 they came with hope and the possibility of a future for people living with HIV/AIDS (PLWHAA) as they were found to improve the quality and length of expected life.[16] The right to ARV treatment became a human rights and equity of access issue and the basis for social mobilisation that resulted in many conflicts in South Africa. The South African government had for years conspicuously ignored local and international demands for broad access to ARV therapy on the grounds of affordability, toxicity of the products, an inadequate health care infrastructure, and issues of sustainability.[17] Hence civil society was, to a large extent, brought into direct confrontation with the state, and as a result began leading the effort to expand access to ARV therapy and promote HIV/AIDS treatment literacy. Since 2003, the Lusikisiki programme achieved universal coverage of ARV therapy with 2,200 people being treated in Lusikisiki (Mèdecins Sans Frontiéres et al., 2006; Nattrass, 2004; Van der Vliet, 2004; Walker et al., 2004; Kauffmann and Lindauer, 2004).

The Lusikisiki programme was designed to be a community-based model, where one of the critical aspects of the programme was an actively engaged community that would support the de-centralized community clinic approach taken. Clinic

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[16] Antiretroviral (ARV) therapy is provided to AIDS-infected people with a CD4+ cell count below 200 (South African criteria). ARV therapy can transform HIV infection from a fatal to a chronic disease.

[17] David Kalombo., *"Treatment: A View from Government*," Nelson Mandela Foundation. *Mèdecins sans Frontiéres*: *A Dialogue on ART Delivery*. At a dialogue on the delivery of antiretroviral treatment in resource-limited settings held at Maropeng, Cradle of Humankind, Gauteng, South Africa, 2006. Dr. Kalombo, who is Manager in the National Department of Health, documents the reasons why the government was reluctant to respond to the demands of rolling out HIV/AIDS treatment. Also see Frank Chikane, *Eight Days in September: The Removal of Thabo Mbeki*. (Picador Africa: South Africa, 2012), pp. 133-134.

locations increased accessibility, and the integration of trained community health workers into the treatment model was intended to ensure community engagement and acceptance of the programme. And according to Mèdecins Sans Frontiéres et al., (2006), the programme was characterized by strong community ownership and participation.

The chronic shortage of professional health workers (nurses, doctors, pharmacists, etc.) remains a major issue in scaling-up ART.[18] This is particularly the case in remote rural areas such as Lusikisiki, where health systems are under-resourced. Lusikisiki currently has 40-50 percent of professional nurse positions vacant, whilst doctors can only be accessed at district hospitals. In retrospect, the comprehensive HIV/AIDS treatment programme implemented in Lusikisiki was made possible through the implementation of a *task-shifting* strategy.[19]

The historic bottleneck caused by a lack of skilled health personnel was solved by enabling lesser trained nurses, with additional training, to manage ARV therapy with the support of community health workers. In addition, trained HIV/AIDS adherence counsellors, community caregivers, and support groups assumed much of the workload that would otherwise be the responsibility of the nursing staff. Overall supervision of the programme staff was managed by a mobile team lead by a doctor. The programme avoided the bottlenecks often encountered in the district hospitals by integrating primary care with ART, "this experience proves that decentralized HIV/AIDS care is the optimal model for rural areas" (Mèdecins sans Frontiéres et al. and Nelson Mandela Foundation, 2005; Mèdecins sans Frontiéres et al., 2006).

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[18]ART stands for Antiretroviral Treatment/ Therapy, and so it refers to treatment with antiretrovirals (ARV drugs). ART and ARV is also used interchangeably.

[19]Task Shifting involves the deployment of lower level health care workers (staff nurses, nursing assistants, administration officers, data capturers and community health workers) under strict delegation of duty protocols in active partnership with doctors.

The Lusikisiki programme was unique in several ways. To begin, it was initiated by an international NGO in partnership with a local advocacy organization, the Treatment Action Campaign (TAC) −a partnership that was unique within existing HIV/AIDS policy and practice in South Africa. It since has been taken over by the Eastern Cape Department of Health and integrated into other government-run health programmes. Further, the model has expanded from a locale-specific to a provincial programme. According to informed observers, the assumption of the programme by the state is likely to affect not just the local community, but also TAC's on-going role in the programme. A newly-founded local NGO, the Adherence Counsellors Organisation (HAACO), was formed to temporarily manage the programme by serving a watchdog function and as the organizational backbone of the programme.

The Lusikisiki programme is also unique in that it reportedly has achieved universal ARV treatment coverage in a deeply rural, impoverished South African community. During a time when state-civil society relations in South Africa were much troubled, Lusikisiki appeared to be an area where the local government and civil society, most notably represented by the TAC, were working side by side to achieve the same programme objectives.

### 1.10 The Treatment Action Campaign: Key influencer in Lusikisiki

Founded on International Human Rights Day, the 10th of December, 1998, the TAC is broadly recognized as a leading civil society force whose mission is to promote access to comprehensive health care services for PLWHAA solidly based on a platform of human rights, patient-directedness, and grassroots advocacy. TAC emerged from a metamorphosis of activists involved in the gay-rights movement during and post-apartheid (Mbali, 2005; Freidman and Mottiar, 2006; www.tac.org). The newly promulgated South Africa Constitution provided the political and constitutional grounding for gay rights activists to launch the TAC with a strong human rights agenda (Mbali, 2005). The distinct and uniquely democratic culture of the post-apartheid government provided the opportunity for

civil society to test the limits of freedom of speech, right of assembly, and right to information. Furthermore, this culture of human rights advocacy provided a new language that was embraced by the TAC in its insistence on greater access to HIV treatment for all South Africans, rich and poor alike. TAC founders faced a welcoming environment in which this new social movement could be birthed.

One notable group that had a strong influence on the TAC was the AIDS Coalition to Unleash Power, also known as ACT UP[20] which was formed in the United States in the 1980s. This group targeted pharmaceutical companies, a common agenda with the TAC, as well as the AIDS research community as well as the U.S. government for what was perceived to be scanty attempts at developing an effective treatment for the HIV/AIDS virus in the first decade of the declared epidemic. ACT UP was notorious for its loud presence, staged 'lie-ins' (as opposed to "sit-ins"), and powerful political slogans−all tactics that were embraced by the TAC's activism strategies. Like ACT UP, the TAC assumed a tough and critical stance on PEPFAR's political agenda.

Another significant and notable catalyst to the formation of the TAC was the life and death of the African National Congress (ANC) leader and gay-rights/AIDS activist Simon Nkoli. This led Zackie Achmat to pledge to drive forward "Nkoli's tussle for openness and the protection of the rights of people living with HIV, especially their right to treatment access" (Mbali 2005: 16). Achmat later wrote in a letter to HIV/AIDS activists in 1998 following Nkoli's death;

> "On Friday night at Simon's funeral I made a call for ten people with HIV/AIDS, their families and friends and allies to start a symbolic fast for access to treatment on 10 December 1998… Openness and treatment are two pivotal issues...A campaign for 'Openness' is in reality a call for activism and the assertion of identity. People with HIV/AIDS are on our own (whether in or out of the closet) - while we should seek love, compassion and care – we should also demand treatment" – Letter from Zackie Achmat.

[20] For more on ACT UP, see Ronald Bayer and Gerald M Oppenheimer, *AIDS Doctors: Voices from the Epidemic* (Oxford: Oxford University Press, 2000).

This call for action was the impetus for the creation of the TAC, a movement to be led by HIV-positive activists who were open about their status - Zackie Achmat, Edwin Cameron, and Mark Heywood. Openness about HIV status became the trademark of the TAC's political and social strategy (Furlong and Ball, 2005; Friedman and Mottiar, 2006).

Unlike the early 1990s when human rights champions and AIDS activists were directing their efforts to ensure a patient's right to confidentiality, in the late 1990s AIDS activists promoted a stance of openness about HIV status as the way to ensure access to health care as inherent right regardless one's health status. This posture led to a "patient-activism" model driven by people living with HIV/AIDS which is characteristic of the TAC that continues to this day.

Today the TAC is an advocacy organization with more than 16,000 members, 267 branches throughout South Africa, and 80 full-time staff members (www.tac.org). Since its founding in 1998, the TAC has held government accountable, campaigned against official AIDS denialism, challenged the world's leading pharmaceutical companies to make treatment more affordable, and cultivated community leadership in the fight against HIV/AIDS. The TAC supports many global initiatives on prevention and treatment. TAC's programmes include: facilitating access to treatment; providing literacy training on prevention and treatment for individuals, and communities; coordinating and distributing research findings about HIV/AIDS and TB; and organizing and advocating with member communities to engage in issues of policy and service delivery. The current government-sponsored treatment programme, Prevention of Mother-To-Child Transmission (PMTCT) largely came about as a result of the TAC's advocacy efforts.

The TAC was founded during a time of political and civic unrest surrounding state policy regarding the HIV/AIDS epidemic in South Africa. Accordingly, the TAC set

its mission and primary goal toward "ensuring access to affordable and quality treatment for people living with HIV/AIDS; the prevention and elimination of new HIV infections; and the improvement of the affordability and quality of health-care access for all" (Friedman and Mottiar, 2004: 28). It was this sense of mission and purpose that informed the role that the TAC assumed in Lusikisiki, advocating for universal access to ARV therapy in a rural and impoverished area in South Africa where inequalities in health care access were most starkly observed.

### 1.11 Thesis Map

This introductory chapter has provided an epidemiologic overview of the HIV/AIDS epidemic in South Africa; specifies the research objectives, questions, and methods utilized to answer the research questions posed; finally, it describes primary elements of the Lusikisiki case study that will form the theoretical and analytical basis of this dissertation study. The remaining chapters are structured accordingly:

**Chapter 2** - *Trajectory of the HIV/AIDS Response in South Africa: The predominant Role of NGOs in Shaping the Response* describes the historic evolution of the state, civil society, and NGOs and their respective roles in shaping HIV/AIDS policy in South Africa with particular attention to the role played by NGOs.

**Chapter 3** - *HIV/AIDS as Development Discourse: Conceptual Considerations* reviews the literature that discusses the various theoretical and conceptual frameworks of international development policy and practice. The chapter pays particular attention to the role of NGOs in defining and shaping the international social and economic development discourse.

**Chapter 4** - *AIDS, Governance, and Civil Society* reviews the scholarly literature on participatory governance, discussing the principles of governance in the context of HIV/AIDS policy and practice. Theoretical assumptions about the respective roles of civic society and the state are critiqued, paying particular attention to power-sharing and how power imbalances have served to shape the

state policy response to HIV/AIDS in South Africa. The particular role of international donors is highlighted.

**Chapter 5** - *International Donors as Agents of Strategic Translation* this chapter discusses the particular and dominate role that PEPFAR has assumed in HIV/AIDS funding in South Africa and globally. Through this global dominance in funding, PEPFAR has been able to set the terms of engagement for recipient countries. In particular, the chapter discusses PEPFAR's emphasis of the tools of monitoring and evaluation reporting systems as a mechanism of control to ensure its development agenda is followed.

**Chapter 6** - *Strategic Alliance: The Tale of an Embedded Partnership* discusses the Lusikisiki Project in the context of its three key partners (MSF, TAC and HAACO) that formed a strategic alliance in Lusikisiki in response to the HIV/AIDS public health crisis. Discussed in detail are the structural and political characteristics of the individual partner organizations as well as the nature of the tripartite alliance that formed.

**Chapter 7** - *Social Mobilisation and the Dual Role of the Treatment Action Campaign* examines the ways in which the TAC used a social mobilisation strategy successfully to the advantage of the tripartite alliance discussed in the previous chapter. The focus of this chapter is on the dual role played by the TAC at both organizing and social media and their impact on the governance dynamics at play in Lusikisiki.

**Chapter 8** – *Messiahs and Pariahs? Cultural Scripts and Liberation Rhetoric* this chapter reflects the stories of prophetic leadership and social change and relate them to the case of Dr. Herman Reuter and his presence in Lusikisiki. The chapter also discusses the local political traditions and cultural idioms and how they intersect with national and even international discourse of resistance and rights claims in the struggle against AIDS denialism. It reveals this through the lens of contrasting representations and perceptions of Dr Herman Reuter and Dr Tshabalala-Msimang in the HIV/AID struggle in Lusikisiki.

**Chapter 9** - *Food and Drugs: Rural Politics and the Ambiguities of Dependence* explores the political dynamics and ambiguities between the needs of the rural

poor to access food in the form of grants and drugs and, the agendas of NGOs of pushing the pill agenda in the face of the HIV/AIDS epidemic in Lusikisiki.

**Chapter 10** - *Media Bias, Local Realities: Representing the HIV/AIDS Crisis in Lusikisiki* this chapter will reflect on some of these media representations and question their validity by reflecting on the contradictions between local practices and media representations.

**Chapter 11** – *The Politics of Transition from NGO to Government Ownership* lays out the organizational and governance transition that occurred when Mèdecins Sans Frontiéres (MSF) departed Lusikisiki. It discusses the consequences of MSF's withdrawal from the community on both the community and the remaining partners, and the impact on local and regional policy and practice decisions.

**Chapter 12** – *Conclusion* discusses the lessons learned from the interactions between the state, international donors, NGOs and civil society in the case study community of Lusikisiki.

## Chapter 2: Trajectory of the State's Response to HIV/AIDS in South Africa and the Critical Role of NGOs

The history of national HIV/AIDS policy in South Africa is among the most complex and controversial of any country dealing with HIV/AIDS on a broad scale. The South African government's response to HIV/AIDS is littered with examples of what has been characterised as "inaction and harmful interference and pseudoscience." Conflicts between politicians, as well as those arising between governmental agencies and civil society are numerous and their effect on the various stakeholders involved continues to be felt today.[21]

Though some people are at higher risk than others of becoming infected with HIV and dying from AIDS, the disease has spread deeply into the general population and is no respecter of social or economic class.[22] It is true that the early manifestations of HIV/AIDS disease in South Africa were contained within the gay community which led to the belief that it was a homosexual disease with the wider population largely ignoring other environmental risk factors and the apartheid government excusing itself from acting. By mid-1991, the number of AIDS cases attributable to heterosexual transmission equalled those of homosexual transmission (Whiteside and Sunter, 2000).

### 2.1 Early State Response

The late eighties and early nineties saw the growing number of HIV/AIDS cases make their way onto South Africa's national domestic agenda. However, in the turbulent political climate of the times, many public leaders and influential groups decried conspiracy with racial overtones attributed to the spread of HIV/AIDS. According to an official publication of the then-in-exile African National Congress

[21] WHO/UNAIDS/UNICEF (2011). "Global HIV/AIDS Response: Epidemic update and health sector progress towards Universal Access 2011"

[22] For decades, the prevailing thought among South Africans was that HIV/AIDS was a disease of the poor. Today, HIV/AIDS is found everywhere, even among the country's rich. Still, there are groups that have been harder hit by the epidemic than others.

(ANC), HIV/AIDS was alleged to have been developed in a laboratory, while others suggested it was spread by police tear gas or through the deliberate infection of black sex workers by ex-ANC collaborators. Conservative parties claimed that whites were being threatened by HIV/AIDS through the desegregation of public facilities (Van der Vliet, 2004).

The first steps to a more rational, coherent response to the epidemic were also taken during this period. The Southern Africa *Maputo Statement on HIV/AIDS* was issued following the 1990 Fourth International Conference on Health in Southern Africa which brought together ANC representatives, other anti-apartheid figures and health workers, as well as those involved in fighting the epidemic in other countries. The document outlined the features needed for a comprehensive response to the epidemic including a focus on prevention and the privacy rights of infected individuals (Heywood and Cornell, 2004).

The formation of the National AIDS Coordinating Committee of South Africa (NACOSA) in 1992 brought together a wide range of individuals to develop a coordinated response to the growing AIDS epidemic and included political parties, trade unions, academics, business organizations, and civic groups (Van der Vliet, 2004). NACOSA's national HIV/AIDS strategy envisioned a broad approach to combating HIV/AIDS with action on all fronts including prevention, research, human rights, counselling and social welfare, involving a number of governmental agencies. South Africa's National HIV/AIDS Plan was adopted within months of the country's first democratic election in 1994; there was optimism that an epidemic on the scale experienced by other African countries at the time could be avoided (Heywood and Cornell, 2004).

### 2.2 Turning the Wheels of Hope

A few years into the 1990s, as South Africa's government transitioned from a policy of apartheid to one of democracy, the HIV infection rate began to rise rapidly. Prevalence rates among antenatal clinic patients (a frequently used HIV

prevalence indicator) rose from 0.7% to 2.2% between 1990 and 1992 (Van der Vliet, 2004).

Although still in the early stages of what was to become a full blown epidemic, it appeared that South Africa was ready to face the epidemic head on;

> South Africa, in 1994, with an infection rate below 5% was ready for the epidemic - ready in the sense of having information about the epidemic in the USA and Europe, ready in the sense of having seen the epidemic in other African states, and Latin America. Ready in having a group of highly literate HIV/AIDS specialists in prevention, care and research that could drive the programme (Crewe, 2000).

However, the actions detailed in the plan that had been so promising never materialized and optimism turned to disappointment. Various reasons have been suggested; among these bureaucratic restructuring and the devolution of state power to provincial governments, which resulted in the lack of a shared, coherent strategy (Crewe, 2000). One commentator noted that this reasoning lacked credibility, that "there is a limit to how long a government can blame its own bureaucracy without being held to account for that failure" (Nattrass, 2004). Another explanation put forth was that other more pressing matters needed attention and that the nascent government preferred to focus on policies that symbolised optimism for the future,

> "It was [also] a time when the new government would prioritize positive programmes, such as housing, jobs, education and wider healthcare issues. AIDS warnings and the message of safer sex were not subjects congenial to those savouring the euphoria of freedom" (Van der Vliet, 2004).

The new government placed the HIV/AIDS Programme Director in the Ministry of Health rather than the President's Office as was recommended in the National AIDS Plan which was interpreted that HIV/AIDS was regarded solely as a health issue rather than a multi-sectorial social issue requiring the coordination of a number of governmental agencies to resolve (Natrass, 2007). This period

marked the beginning of an era that characterized South Africa's governmental response to the HIV epidemic in negative ways. One often cited example of this negativity was the controversy surrounding the AIDS awareness screenplay, Sarafina II.[23]

Quickly following the production of Sarafina II was another equally damaging scandal associated with the government's HIV/AIDS strategy when an antiviral treatment known as Virodene was being tested on a small scale by researchers at the University of Pretoria. South Africa's drug regulatory authority, the Medicines Control Council (MCC), refused to allow the researchers to continue with the trials believing Virodene was dangerous and that the trial protocol had not been carried out as approved. This decision led to the researchers to portray themselves as victims of the HIV/AIDS establishment and appealed to the government for support. These incidents marked the beginning of the politicization of South Africa's policy approach to HIV/AIDS.

**2.3 Fighting for ARV drugs**

The first major battle over access to antiretroviral drugs (ARV) was for AZT, also known as Zidovudine. This life-saving drug was for the prevention of mother-to-child transmission (PMTCT). In 1998, it was announced that a trial using a short course of AZT in Thailand had cut the mother-to-child transmission rate in half. This led South African advocates and researchers to call for the drug to be provided to pregnant mothers. Mark Heywood, of the AIDS Law Project and one of the founding members of the Treatment Action Campaign wrote,

> "Our country cannot afford 50,000 children being born with HIV this year and an increase on that number next year and an increase on that number for many years to come" (CNN, 1999).

[23] See Natrass (2004), *The Moral Economy of AIDS in South Africa* for details about Sarafina II and the controversies surrounding the musical-based screenplay.

However, the use of AZT was rejected in most of the provinces on cost grounds despite the manufacturer cutting the price and economists believing the use of AZT would result in cost savings.

The Treatment Action Campaign (TAC) founded by Zackie Achmat in 1998, who would later become a Nobel Peace Prize nominee for his advocacy efforts, was launched specifically to promote broader access to AZT drug treatment. The group grew into one of South Africa's leading voices for the rights of people living with HIV/AIDS (PLWHAA), directing its energy towards the government and pharmaceutical companies whose policies they believed stood in the way of people receiving treatment. Achmat, himself HIV positive, publicised the situation by refusing to take his ARV medication until it was available to all South Africans.

The departure of Dlamini-Zuma as then Minister of Health, following the controversy over access to AZT drugs and her growing conflict with HIV/AIDS organizations, led to her replacement by the late Mantombazana Tshabalala-Msimang, affectionately referred to as 'Manto'. Her appointment was greeted with optimism as she willingly met with NACOSA, drug manufacturers, doctors, and community-based organizations. However the optimism quickly faded away as she, and the then newly-elected President Thabo Mbeki who had appointed her, brought to the discussion the possible side effects and toxicity of AZT. Mbeki claimed that AZT was toxic, and along with Manto, publicly decried that the drug weakened the immune system and could led to genetic mutations in infants (Van der Vliet, 2004). Similar arguments were made against Nevirapine, another antiretroviral drug for prevention of mother-to-child transmission. This new claim was made despite the recent Ugandan trial showing that a single dose substantially reduced the risk of infection (Guay et al, 1999).

### 2.4 HIV/AIDS Denialism under President Mbeki[24]

> "I have searched for the definitive statement by Mbeki in which he denies the link between HIV and AIDS. I have not found it…" (Njabulo Ndebele).
>
> "…it is true that Mbeki has not expressly or publicly "ever denied a link between HIV and AIDS" (Mark Heywood).

The arguments and policies against providing access to AZT and Nevirapine were personified by President Mbeki and Minister of Health Manto Tshabalala-Msimang. The public debate soon evolved into a much broader questioning of all antiretroviral drug therapy, including those used for treatment of the active disease. This debate became known as denialism, which argued that HIV did not cause AIDS and instead resulted from socio-economic factors and lifestyle choices. Tshabalala-Msimang began advocating for the value of good nutrition in repressing the virus and stating, "I don't know many (South Africans) with HIV who would want to take antiretrovirals." These kinds of statements resulted in her being labelled "Dr. Beetroot". At the 16th Annual Global AIDS Conference in Toronto, the South African Department of Health presented a display of garlic, lemons and beetroot, with bottles of ARV drugs added after complaints were made.[25]

The South African scientific community expressed dismay at the fact that dissident views on HIV were guaranteed greater prominence when President Mbeki created the Presidential AIDS Advisory Panel and sought its advice on issues including the appropriate use of antiretrovirals and whether HIV caused AIDS. The inclusion of both HIV scientists and AIDS denialists effectively afforded greater prominence to the denialists' position which would not have had such a high profile. Nattrass reported that Mbeki's approach to seeking scientific

[24] Many scholars have written about AIDS denialism in South Africa, some labelling Thabo Mbeki as an AIDS denialist while some remained sympathetic. See Gevisser, 2007; Roberts, 2007; Mangcu, 2008.

[25] Journ AIDS (2012) 'The Politics of HIV in South Africa' - See more at: http://www.avert.org/history-hiv-aids-south-africa.htm#footnote29_tk4blq0

truths was not sufficiently informed by the scientific community as represented by the Medical Research Council (Nattrass, 2007). Comments made by South African scientists reinforced their lack of appreciation for the Presidential AIDS Advisory Panel and its known biases, “As long as Mr Mbeki is being advised by people with no credibility we as South African scientists feel dangerously marginalized in the search for solutions to HIV/AIDS.”

The Presidential AIDS Advisory Panel was viewed as more than an arena for honest debate, but rather as Nattrass, the then Director of the AIDS and Society Research Unit at the University of Cape Town, observed, “The panel served as a means for Mbeki and the Health Minister to portray AIDS science and policy formation as deeply contested and contestable. This in turn provided them with the space to resist the introduction of AZT and other ARV drugs on the grounds that ‘more research was needed’ into their toxicity and effectiveness” (Nattrass, 2007).

**2.5 Shaping Government’s HIV/AIDS Response**

Official state responses to HIV/AIDS and their concomitant intervention strategies are shaped by many influences and approaches. However, the two dominant approaches that previously shaped the way many countries thought about and subsequently responded to the HIV/AIDS epidemic can be characterized either by a “...biomedical lens [or] secondly through a narrow public lens that has focused on individual sexual behaviour” (O’Manique, 2004). Likewise Campbell asserted in 2003 that “HIV *science* is dominated by behavioural and biomedical research studies...”

In recent years, however, these dominant approaches have come under increasing attack for failing to take into account the complexity of the epidemic in terms of the social and economic factors that facilitate the spread of a disease into epidemic proportions (Campbell, 2003; Nattrass, 2004; O’Manique, 2004; Barnett and Whiteside, 2003; Vliet, 2004; Waal, 2006; Farmer, 2005). These

structural approaches argue that there is a need to improve our understanding of the HIV/AIDS epidemic taking into account the inequalities that exist within society, particularly resulting from poverty. Fassin argues that there is an urgent need to deal with the mechanisms that shape how "...the security of a minority is bolstered and fuelled by the insecurity of the majority." (Fassin, 2007)

It is from the recognition of the critical nature of the structural determinants of the spread of a disease that an understanding of former President Thabo Mbeki's stance on HIV/AIDS, no matter how controversial, derives. Nauta candidly observed that, "He [Mbeki] is critical about the stereotypes used to depict Africans and some of the central assumptions about African sexuality that underlie the behavioural model, and demands attention for the relationship between poverty and HIV/AIDS" (Unpublished 2010). High Court judge Edwin Cameron, a noted HIV advocate, concurs with Wiebe's position when he states that "...Mbeki's stance on HIV/AIDS [was] based on an environmental approach, and therefore needs to be understood as such, hence from that stand point and approach he is not wrong" (Interview, Tuesday 17 January 2012).

Stillwaggon, an expert in the science of HIV/AIDS, was among the non-denialists scientists to acknowledge the relevance of Mbeki's probing questions about HIV and AIDS;

> "Thabo Mbeki had the temerity, as some Western scientists viewed it, to ask how conditions of poverty in Africa affect the development of HIV/AIDS. It was a very controversial epidemiological question, well within the bounds of standards of research. His question was treated, however, as heresy by at least a vocal minority of mainstream scientists, who seemed to regard any inquiry as beyond his prerogative" (Stillwaggon, 2001).

South Africa's current HIV/AIDS policy is considered by some to be the best in the world (Chikane, 2013). The policy framework is laid out in South Africa's National Strategic Plan which has not changed since its adoption more than a decade ago. In 2007, South Africa was acknowledged as having the largest

HIV/AIDS treatment programme in the world, with approximately 370,000 people on ARV treatment in the public sector and an additional 120,000 on ARV therapy in the private sector. Spending on HIV/AIDS treatment increased from US$479 million in 2004-05 to US$878 million in 2009-10.

The July 2008 UNAIDS Country Situation Report noted that South Africa had adopted a comprehensive set of HIV/AIDS policies and programmes that included disease management, ARV treatment, on-going care coordination, research, and programme monitoring and evaluation (UNAIDS, 2009). Further, under the leadership of Mbeki, the government revamped the National AIDS Advisory Council into a multi-sectorial body to provide high-level leadership and policy coordination as well as being responsible for the development of the five-year National Strategic Plan (NSP). In sum, South Africa's political, policy, and institutional response to the HIV/AIDS epidemic has varied over time (Ballard et al., 2006).

### 2.6 NGOs as Partners in the Fight against HIV/AIDS

Widespread pressure for inclusive participatory engagement of civil society and a declining faith in the capacities of government to solve the interrelated problems of social welfare, development, and the environment, lead to a global upsurge of privately organized activity through non-profit, nongovernmental organizations, i.e., NGOs (Nauta, 2012). The NGO sector has grown increasingly important in its efforts to alleviate social problems and injustices and promote democratic values. The NGO sector has become a major economic force with sizeable contributions to national and local economies, including paid employment (Salamon, 1997).

Development agencies, human rights activists, indigenous peoples, and other defined interest groups have become activate participants in international community-building activities as a result of the proliferation of NGOs. Since their inception, the United Nations (UN) and its various affiliate organizations have felt

the direct and indirect impact of NGOs, they are omnipresent in many aspects of international relations and have become critical to the UN's future (Salamon, 1997). NGOs have assumed a central role in activities involving human rights violations, humanitarian emergencies, global environmental concerns, the international women's movement, and global health concerns, including the HIV/AIDS epidemic. They importantly bring local experience to bear on international policy decision- making (Gordenker and Weiss, 1996).

The NGO expansion, dubbed the *barefoot revolution*, has been attributed to several external and internal environmental factors (Slates, 1993; Gordenker and Weiss, 1996). Three of the more important factors include the end of the cold war, technological developments, and the growing availability of resources. The end of the Cold War was the first and perhaps most important influence on NGO expansion as it brought with it an end to ideological and social orthodoxy (Peet and Hartwick, 1999). UN diplomats were less reluctant to interact with non-governmental staff, opening up new avenues of communication and cooperation within the international policymaking process (Escobar, 1995). As a result, the UN became a forum for discussions between governments and NGOs. Previously, when politics and national security, especially nuclear proliferation, dominated the international agenda, NGOs were at a comparative disadvantage because they were not purveyors of weapons and therefore had only limited access to people in decision-making positions. Since the end of the Cold War, NGOs have had increasing access and the capacity for direct participation in policy discussions (Escobar and Harcourt, 2002).

The development of new technologies has been widely accepted as a primary factor in the growing prominence of NGOs in UN activity. In the past, governments hostile to the NGO sector were able to prevent information flow and the ability to network with others with similar interests through various forms of telecommunications. The greatly expanded options for electronic communications, especially the internet, have made it possible to circumvent

national borders, and create virtual communities based on common values and objectives that were once the exclusive privilege of official state entities (Gordenker and Weiss, 1996).

The third factor is the growing access to resources and resulting professionalism achieved by NGOs. Local and international NGOs have garnered a growing pool of resources from individual donors, governments, the UN and other international non-governmental organisations. Western governments, for example, have increasingly funded NGOs on the basis of their reputations as cost-effective, high quality organizations. New telecommunications technologies have helped to foster interactions and relationships that were once possible only through air travel. Scaling up internationally-funded projects from neighbourhoods involving local grassroots organizations to regions and the global level are no longer logistically impossible (Gordenker and Weiss, 1996).

Increased networking capabilities have improved donor capacity to monitor NGO compliance with accountability standards, promote innovation, and hold failed or failing projects accountable. In response to this oversight, NGOs have developed a range of organisational accountability tools from formal structures to informal collaborations to increase their efficiency. Included among these collaborative strategies are formal bridging groups, federations, UN-sanctioned coordinating bureaus, and direct connections to governmental agencies (Gordenker and Weiss, 1996).

Based on their review of the evolving roles of NGOs, Gordenker and Weiss suggest that NGOs have two important societal functions: 1) operational and 2) education and advocacy (1996). Operational NGOs have become a primary vehicle for responding to disasters and other national crises through the rendering of direct services; support for the provision of these services most often comes from public and private donors. Services rendered by operating NGOs include technical assistance, disaster relief, community-based health and

human services in response to epidemics, unstable public sector agencies, and inequities in access to critical health and human services. Alternatively, education and advocacy-oriented NGOs exist to educate citizens and communities about important social issues and seek to shape public opinion through the media and local organizing efforts. These NGOs reinforce positive community norms through public education campaigns (Gordenker and Weiss, 1996).

NGOs are often locally created and staffed, thus ensuring their credibility with and understanding of the communities they serve. Locally formed NGOs are more likely to mobilize community members in local efforts because they are also more likely to be responsive to local customs and norms, and as such, increase the probability that community problems are appropriately addressed because of this sensitivity to uniquely local circumstances. Committed volunteers and staff paid at local wages provide the energy, resources, and personal commitment to organizational goals to ensure the NGO meets its targeted service areas (Mercer et al., 1991; NORAD, 1991).

Since NGOs are often staffed with volunteers or modestly paid staff, they are at increased risk for staff burn-out. The need to maintain an optimum balance between paid and volunteer staff to maintain organizational viability is especially important in the emotionally demanding field of human services to vulnerable populations, with HIV/AIDS treatment services being one such programme area (ACORD and ACTIONAID, 1997; Brodhead and O'Malley, 1989; Brown and Korten, 1989; Crane and Carswell, 1990; Johnson and Soderholm, 1994; Mercer et al., 1991; NORAD, 1991; Shreedhar and Colaco, 1996).

What stands out in the above referenced discussion of the NGO literature is the importance of inclusion−inclusion of community stakeholders and the recipients of services in the programme development process. Nyamwana made a strong case for this inclusion, particularly in the health care sector when he stated that,

> "… while in theory communities are supposed to play a leading role in the health-development process, the process is still largely controlled by government and NGO development 'experts' who do not allow communities to play major roles" (Nyamwana, 1997: 98 as quoted in Nauta, 1999).

### 2.7 NGOs and Neoliberalism

Although neoliberal policies have shaped much of the landscape of various national and local political struggles, they are by no means hegemonic. NGOs at the local level have been central in challenging local government officials to provide needed health and human services and infrastructure improvements services for local communities. NGOs work with existing governance structures to ensure that services that meet the needs of the community are provided (Mindry, 2008).

Not all NGO activity however challenges neoliberal governance policies. For example, many NGOs in South Africa have been drawn into servicing the neoliberal agenda of international donor agencies as well as the South African government. NGOs can challenge neoliberal ideals or they can support them. In sum, NGOs do not simply support or challenge a neoliberal agenda but rather navigate a complex political field that has been shaped in part by neoliberal ideologies but also by a legacy of civil disobedience and struggle as seen through an historic lens of self-reflection (Mindry, 2008).

### 2.8 AIDS-related NGOs in South Africa: A Retrospective View

At a high policy level, the HIV/AIDS Plan developed by NACOSA in 1992 was the first official government response to the HIV/AIDS epidemic in South Africa. Although the plan proposed a multi-sectorial structure including the ministries and departments of health, welfare, education, and defence, it did not gain traction as it was introduced during a political transition when the government was focused on other presumed higher priority issues (Nattrass, 2004).

In lieu of this coordinated, multi-sectorial state response, the response to HIV/AIDS in South Africa prior to 1994 was largely led by NGOs, public health researchers and health workers who created a network of organizations that provided HIV counsellor training and prevention-oriented information dissemination (Schneider and Stein, 2000).

In 1994, The Soul City Institute for Health and Development was established with the aim of providing education and behaviour change to individuals suffering from HIV/AIDS. Combining primetime television and radio dramas, coupled with the distribution of print materials, the Soul City project raised awareness among the public through debates and by promoting behaviour change. As such, Soul City was a pioneer of using a mass media campaign to promote behavioural change. Although its predecessor, the Beyond Awareness Campaign which established a free AIDS Helpline in 1992, also using the media to inform the public about HIV/AIDS.

In the late 1990s, the Treatment Action Campaign (TAC), and Lovelife, both South Africa-based NGOs, focused their advocacy efforts on messaging about sexual health to youth who are among the most vulnerable risk groups in the fight against AIDS. Lovelife was founded to reduce teenage pregnancy and the spread of HIV/AIDS and other sexually transmitted infections (STIs) among the youth population. In 2001, the AIDS Communication Team (ACT) was founded, initiating a two-year media campaign to educate the public about the dangers of unprotected sex and its relationship to HIV/AIDS. With the exception of the TAC, the other three HIV/AIDS advocacy campaigns that utilized the media as their primary messaging device were rarely acknowledged for the role they played in informing the state's policy response to HIV/AIDS although they collectively played a pivotal role in communicating the importance of prevention in slowing the spread of HIV/AIDS in South Africa.

More recently, the South African National AIDS Council (SANAC) was established by government in 2002 to unite governmental and civil society efforts in the fight against the HIV/AIDS epidemic. The SANAC is currently the highest national body providing policy guidance, support, and monitoring of HIV/AIDS programmes. The SANAC was designed and implemented to engage the state, civil society, and the private sector and to coordinate their combined efforts to eradicate the HIV/AIDS epidemic (Strode et al., 2004). The sectors represented on the SANAC Executive Committee include health, labour, agriculture, transportation, defence, traditional leaders and healers, youth, women, the hospitality sector, and people living with HIV/AIDS.

Shortly after its creation, the SANAC recommended the formation of Provincial AIDS Councils (PACs). Each province was asked to set up a PAC to be in conformance with the National Strategic Plan (NSP) which sought to coordinate local community efforts in lieu of dependency on the National Department of Health (Hickey et al., 2003). The Eastern Cape AIDS Council (ECAC) was the third provincial council to be established in South Africa. The ECAC set about to coordinate its activities with the NSP and established District AIDS Councils at local level (ECAC, 2005).

In 2006, the National Department of Health announced the restructuring of the SANAC and appointed the deputy president as its chairperson. Some have argued that the re-structuring reflects weak operational policies and a lack of strategic planning (Strode et al., 2004).

In the post-apartheid era, South Africa has witnessed a sizable growth in the number of HIV/AIDS-related NGOs. Within the context of an increasingly empowered civil society, the number of HIV/AIDS-focused NGOS greatly expanded in response to the demographic, economic, and social imperative brought about by the societal impact of the disease (Brower and Chalk, 2003; Chirambo, 2006). The number of newly established NGOs in the South African

health sector increased from 598 (pre-1976 period) to over 2000 in the period between 1994 (the end of apartheid) and 2002 (Swilling and Russell, 2002). It has been estimated that HIV/AIDS-related NGOs in South Africa now “constitute the bulk of policy interventions and service delivery actors” (Seckinelgin, 2008: 42).

NGOs increasingly have been engaged in the delivery of alternative health care options in Africa (Loewenson, 2003; Julie, 2009). Not only have they been viewed as a positive activist force in influencing policy formulation and implementation, they are also recognized as a service delivery alternative to government-run primary health care services.

More than any other country on the African continent, South Africa has attracted HIV/AIDS funding international donors, both private and governmental. In fact, large international donor agencies have become major benefactors in response to the HIV/AIDS epidemic in South Africa. It has been noted however that these donor agencies have a significant amount of influence over program design and implementation (Porter, 2003; Bornstein, 2005). In some instances, the lifespan of donor commitments has proven to be short, thus making the sustainability of their initiatives unsustainable. However the lifespan of big international donor agencies such as PEPFAR have been consistent in their funding commitments for the past decade and there are no signs that this commitment will be diminished in the near future. PEPFAR has changed its focus more recently from supporting NGOs in the provision of direct prevention and treatment services to technical assistance focusing on health systems strengthening.

HIV/AIDS activities initiated by South African NGOs have had an uneven influence on the policy decisions made by the public governmental sector. In the case of being a positive influence, many factors were involved including the intrinsic advantage enjoyed by NGOs that operated cooperatively with local communities as opposed to the state which was a reluctant community partner,

lacking timeliness in its response to the HIV/AIDS epidemic (Parikh and Whiteside, 2007). Since HIV/AIDS in South Africa was inextricably linked to issues of morality, behaviours that were illegal or socially unacceptable such as illicit drug use, homosexuality, or commercial sex work, often were considered primarily responsible for the spread of the disease. As a result, many South African governmental leaders found it difficult for political, economic, and social reasons to admit that these behaviours existed (Gevisser, 2007).

NGOs were able to respond quickly at a community level partly because they were not hampered by bureaucracy and partly because they were in close proximity to the constituencies they served. As such, they were better positioned to understand local culture, norms, and belief systems. NGO action, both on a local level and through advocacy efforts at the national level, often led the way in achieving equity of access for PLWHAA. Notwithstanding this decisively positive role, NGOs often faced difficulties in bringing programmes to scale because of their over-reliance on external funders with money that often dried up prematurely or was restricted to certain programme elements to the exclusion of others (Bornstein, 2005; Pisani, 2008). Local NGOs and the communities they represented were often placed in a position that required following the programmatic lead of well-funded international NGOs. From the early years of the epidemic, international NGOs dominated the response to HIV/AIDS, and led the way in communities like Lusikisiki, the subject of this case study.

### 2.9 The dynamic nature of the state, donor and NGO relationships

Since 2002, there have been increasing commitments and additional financing for access to treatment for people living with HIV/AIDS in South Africa. Major international donors include: WHO, UNAIDS, the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), the Global Fund to Fight AIDS, TB and Malaria, and the latest G8 and UN Summit commitment to fund universal access to prevention, treatment and care for all those who suffer from HIV/AIDS, originally by 2010, and now revised to 2015. The HIV/AIDS political and policy landscape

has shifted significantly at international, national and sub-national levels. Separate development agencies that bypass established state systems and often ignore locally identified needs have been established to manage and disburse these international donor funds and often involve contracts with NGOs providers.

However, despite the nearly five million HIV-positive South Africans, by 2003 state's response to HIV/AIDS continued to be characterised by gaps between rhetoric and reality. And this is still a notable character throughout the South African government's response to the battle against HIV/AIDS to-date. Furlong and Ball write; "The lost opportunities, the grandiose yet ineffective initiatives, and endless delays in policy implementation to fight HIV/AIDS intensifies and allotted funds grew geometrically." (2005). To be fair, however, there were and are some notable efforts and change in various phases of HIV/AIDS response in South Africa.

## Chapter 3: HIV/AIDS as Development Discourse: Conceptual considerations

In his book, "*The History of Development: From Western Origins to Global Faith"* (1997), Gilbert Rist discusses how the colonization of Africa, Asia and Latin America following World War II was the precursor to a new form of imperialism and market colonization. He argues that this development discourse assumes the dependency of developing nations on developed countries as a natural evolutionary process, a universal reality. Through the lens of international development, improvements in economic and social infrastructure are seen as linked to the natural evolution of emerging societies. Rist explains that this development agenda which unfolded in the post-World War II years was largely facilitated by the U.S. government in cooperation with an array of international organizations, among these the United Nations (UN), the World Bank, and the International Monetary Fund (IMF).

Escobar (1994) poses an alternative to this development discourse when he questions how the development models designed by the industrialized nations of North American and Europe came to be accepted as the preferred nation-building strategy for Asia, Africa, and Latin America. Further, how this prevailing development discourse was able to establish the notion of a "Third World" in need of assistance from more developed nations. He argues that the post-war development policies of the West became mechanisms of control in much the same way as those of their colonial predecessors.

In his landmark book, *Encountering Development: The Making and Unmaking of the Third World,* Escobar traces the factors that led up to the dominance of a West-imposed development agenda at the end of World War II. Utilizing a set of analytical tools refined by Foucault, he engages in discourse analysis that examines the phenomena of international development through the linguistic structures that give it meaning and subsequently shape the thoughts and belief

systems that he refers to as the "development apparatus." His theoretical approach shifts the discussion from one of examining the attributes and outcomes of international development policies to one of an interpretivist or a post-structuralist economic development policies for emerging economies. He argues that to weaken or substitute prevailing development ideologies requires the active involvement of social movements that challenge the discursive foundation of the development apparatus and open space for a post-development discourse.

Escobar outlines the common features of post-development thought and offers a vision of an alternative to international development that is embedded in local culture and indigenous knowledge. This post-development thought takes its inspiration from vernacular societies, the informal sector, and austerity as opposed to materialism. Post-developmentalists believe that economies must be based on solidarity and reciprocity; governance that is based on participatory democracy; and traditional knowledge systems, or at least a hybrid of modern and traditional knowledge (Escobar, 1995).

Influential post-modern thinkers like Foucault have challenged the validity of modernist theory and its underlying assumptions about the persistent pursuit of development with an emphasis on rationality and universalism; alternatively, they embraced pluralism. Through discourse analysis an awareness was brought to the fore that what lies beneath meaning can affect actions and outcomes. Post-modern philosophers assert that language always involves a representation of reality. Language cannot simply be regarded as a neutral instrument of communication (Turner, 2000).

Post-modern development theory emerged in the 1980s as a rejection of earlier theories of development. Prolonged periods of authoritarianism and the market-driven policies of the IMF and the World Bank that evangelised the promise of privatisation through structural adjustment programmes largely undermined

political structures and rendered states unable or unwilling “to direct or intervene in the economy on behalf of the poor and the disadvantaged” (Brohman, 1996: 43). The divide between the wealthy and those living in “dehumanizing poverty, servitude and economic insecurity had become undeniable” (Korten, 1995 as quoted in Allen and Thomas, 2000). Sachs considered development “a ruin in the intellectual landscape” (Sachs as quoted in Allen and Thomas, 2000), not only because it lacked results, but also because of its Euro-American centric world-view characterised by an economic and reductionist view of existence (Pieterse, 2000). Each of these critiques resulted in alternative development (post-development) theories generally referred to as participatory development (Parfitt, 2004).

### 3.1 Gaps between Policy and Practice

In his book *Cultivating Development*, David Mosse (2005), a development anthropologist, presents a different perspective on the relationship between policy and practice in the economic development discourse. Using a case study from the British Department for International Development (DFID) of an agricultural development initiative in Western India, he discusses the gap that unfolded between an international development agency and a local community. He discusses this project in the context of two dominant but opposing theories, arguing that neither instrumental nor critical theory could explain the role of policy in explaining the gap between policy and practice that occurred. He demystifies the instrumental perspective that rational policy leads to rational practice and instead argues that policy decisions always result in unintended consequences, entrenched ideologies, and unequal power relationships.

Mosse discusses how development practice informed subsequent policy by demonstrating how DFID policy responded to evolving development paradigms; that is, from participation, to sustainable livelihoods, and subsequently to state level partnerships.

Acknowledging the role of policy in development practice, Mosse makes five propositions:

1. Policy's primary function is to mobilize and maintain political support; that is, to legitimise rather than orientate practice.
2. Development interventions are driven not by policy but by exigencies of implementing organisations and their need to maintain relationships.
3. Development projects maintain homeostatic through political coherence as systems of representativeness as well as through operational systems.
4. Projects do not fail, they are modified by wider networks of support and validation.
5. Success and failure are policy judgements that obscure project effect. (2005: 14-19).

These propositions reflect a hegemonic discourse about participatory development as demonstrated in the DFID initiative, other similar interventions in Africa, and in particular, the Lusikisiki programme as I shall illustrate in the current study. According to Mosse (2005), the DFID initiative in India engaged the language and policy of participatory development. He illustrates how the concept of participation can be hijacked by local elites and how local knowledge is influenced by outside experts and how under the guise of participatory policymaking it possible for the varied actors, e.g., NGOs, governmental agencies and commercial enterprises to work together in shaping programme goals. Similar examples can be found in the case of conservation projects (Wells and Brandon, 1992; Larson et al., 1998) and health (Mashinya, 2007). In the case of HIV/AIDS development programmes in South Africa, particularly the Lusikisiki HIV/AIDS programme, the current study illustrates the intended and unintended policy effects of international development efforts in HIV/AIDS programming in South Africa.

### 3.2 Knowledge and Power

It is not possible for power to be exercised without ascribed knowledge; therefore knowledge engenders power (Foucault, 1981: 52). Discourse is not simply the construction of meaning; it is also the negotiation between elites about how meaning translates into knowledge. It is through this negotiation that the construction of meaning takes place and power relationships are established, "the criteria of what constitutes knowledge, what is to be excluded and who is designated as qualified to know, involve acts of power" (Foucault, 1981 cited in Hobart, 1993:9). Therefore, "not only is discourse always implicated in power; discourse is one of the 'systems' through which power circulates" (Hall, 1996:204). This view holds that certain types of knowledge are privileged, while others are excluded, therefore imbuing power to some and not others.

### 3.3 Indigenous Knowledge and the Development Discourse

As commonly used in development literature, the term indigenous is meant to emphasis the culture of a localized population as opposed to more globalised cultural norms.[26] Indigenous has been used to refer to the "unique, local knowledge of particular cultural groups" (Warren et al, 1995), while the UNCCD describes it as "people-centred, systemic, experimental, very old, forgotten techniques" (UNCCD, 2005: 51). People-centeredness refers to local knowledge that is generated and transmitted by knowledgeable, competent and entitled local community members, while systemic is that aspect of local knowledge that is inter-sectorial and holistic (UNCCD, 2005). Authors such Feyerabend (1975) argue that local knowledge can be viewed as "a valuable resource" that allows "its holders to exist in harmony with nature" (1975: 1).

What is important to recognise is that local knowledge is not static but continually changing and evolving, as cultural groups innovate, borrow, and adapt their cultural norms to changing circumstances (Agrawal, 1995; UNEP, 1998;

[26] Culture refers to symbols through which members communicate their worldview, value-orientations, ethos, and all the rest to one another, to future generations (Geertz 1973).

Dugdeon and Berkes, 2003). As such, local knowledge can be viewed as a diverse, dynamic pool of locally shared knowledge and tradition. This knowledge covers all aspects of local communities such as ecology, agriculture, medicine and health.

Over the past two decades local knowledge has been increasingly acknowledged by scholars and development practitioners. Soeftestad (1998) suggests that local knowledge is important as "it represents the successful ways in which people have dealt with their environments" (1998: 4). Further, he argues that tapping into local knowledge can enhance communication between outside agents and local people, and "help find the best solution to a development problem" (1998: 6). In the book, *Local Understanding of Land: Traditional Ecological Knowledge and Indigenous Knowledge*, Dudgeon and Berkes point out that "researchers tended to advocate the external preservation and exploitation of local knowledge by development agencies, without insisting upon the safeguarding of the local cultures that produce it" (2003: 78), so too do Maruthi and Srivanas (2006).

**3.4 Local Knowledge and HIV/AIDS**

In times of crisis, there is a tendency in local communities to rely on expert knowledge and the special wisdom possessed by external agencies (Holland and Blackman, 1998; Mintzberg, 2010). These external agencies (e.g., donors, NGOs, churches, mosques, and synagogues) are imbued with legitimacy to prescribe solutions to community problems; in this case, the HIV/AIDS crisis. It has been argued that local knowledge has been totally ignored and devalued by international donors in HIV/AIDS development policy and programming (Fowler, 2000; Porter, 2003). It is furthered argued that while external agencies possess expertise and special knowledge, this knowledge should not dominate at the expense of local knowledge and customs. Accepted Western knowledge works in many contexts, but it does have limitations in its effectiveness when ignoring local customs and norms (Mintzberg, 2010). The knowledge found in local

communities is first-hand and based on history, culture, and experience.[27] Local knowledge does not exist in a vacuum, it belongs to a community and is gained through community embededness (Semali and Kincheloe, 1999). As such, in assisting communities to deal with HIV/AIDS, local knowledge, customs, and involvement should not be taken lightly. It has been argued that the role of external agencies is to tap into local knowledge through listening and learning, not to impose external solutions that are devoid of local context (Holland and Blackman, 1998; Dutta 2011).

The reality of the HIV/AIDS epidemic in African nations is a devastating reality that has been well-documented (Gevissier, 1999; Mangcu, 2000; Nattrass, 2004; Van der Vliet, 2004; Kauffmann and Lindauer, 2004). Policies and programmes to reduce the spread of HIV/AIDS and mitigate its impact need to be contextualised by involving local communities. Despite huge amounts of financial and human resources devoted to HIV/AIDS development assistance, containment of HIV/AIDS has proven to be a complex and difficult process. The epistemology of knowledge that underpins international HIV/AIDS development policy is far from objective and value-free. Understanding that the international response to the HIVAIDS epidemic is the product of a social construction, and that the resulting knowledge is political, it largely reflects the vested interests of the most powerful actors involved (Foucault, 1972).

### 3.5 Dominance of the Bio-medical Model

The bio-medical model has dominated the international response to HIV/AIDS policy and practice. This focus has a great deal to do with the power of the medical and pharmaceutical professional institutions and their dominate expertise in the production of scientific knowledge based on clinical research.

[27] Studying the relationship between South NGOs, international NGOs and Northern NGOs working on poverty reduction in Ghana, Porter (2003) observes that local knowledge about poverty is erased by dominant articulations by international knowledge-production bodies. Even in instances where NGOs directly interact with local community members who live in poverty, external epistimologies often override the knowledge gained by the lived experience of poverty that is grounded in the day-to-day struggles of the poor (Fowler 2000; Porter 2003).

O'Manique observed that "very few disciplines rival medical science in its ability to assemble a body of knowledge established through text, journal articles, and clinical studies" (2004:17).[28] The biomedical response to HIV/AIDS has become the lens through which the epidemic is viewed. He argues that two dominant approaches have shaped the international response to the HIV/AIDS crisis, these include the "...biomedical lens, and secondly through a narrow public lens that has focused on individual sexual behaviour" (2004: 29). Likewise, Campbell asserted that "HIV *science* is dominated by behavioural and biomedical research studies..." (2003: 9).

In recent years the exclusively biomedical response to HIV/AIDS has increasingly come under attack for failing to take into account other factors such as social (Campbell, 2003), economic (Nattrass, 2004; O'Manique, 2004; Barnett and Whiteside, 2003), political (Vliet, 2004; Waal, 2006; Farmer, 2005) and the structural factors that are implicated in the spread of HIV/AIDS.

### 3.6 Defining the Problem: Crafting the Solution

Ferguson pointed out that a critical part of the development process is the way in which the object targeted for development is defined. In the case of Lesotho, the country's history as a grain exporting region was totally disregarded, as was its role as a labour reserve for the South African mines. Not wanting to deal with South Africa's Apartheid government, international development agencies partitioned off the independent state of Lesotho from the rest of South Africa's economy in which it was enmeshed in the development of the rationale for their intervention projects. Artificially taken out of this larger capitalist context, Lesotho's economy was therefore described as "secluded," "non-market" and "traditional" and therefore an appropriate target for international aid (Ferguson, 1990).

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[28] Mainstream biomedical practitioners hold that the HI-virus is the etiological agent and that treatment entails treating the infections that result from lowered immunity and prescribing antiretroviral medication to inhibit the growth of the virus itself (Downing 2005: 24).

Ferguson further argued that development interventions are implemented within an institutional setting which must demonstrate a legitimate role for governmental intervention. Rose added that a development strategy that suggested that poverty, its causes and effects, was outside the scope of government would be quickly dismissed because it would no longer provide a legitimate rationale for state action. He goes on to argue that a capitalist economy which assumes a marginal role for the state must engage in a discursive exercise that deems native economies as underdeveloped and therefore an appropriate target for state intervention (Rose, 2006).

The HIV/AIDS epidemic resulted in an overwhelming demand for antiretroviral therapy. This demand translated into a demand for reasonably priced pharmaceuticals to reach the most impoverished populations in a timely fashion. Access to ARV therapy has become the dominant intervention approach used by international donors, and by association, the NGO sector that receives donor funds.

As discussed in this chapter, there are varying levels of agreement about the appropriateness of prevailing international development policies and practices with regards to the HIV/AIDS epidemic. However, the development discourse centres on the relationship between development policy and practice and forms of governance. It is generally agreed that development policy and practice is determined by the structure of governance, and the form that governance takes is likewise is shaped by development strategies (Edwards and Hulmes, 1992).

Because development theory equates development with national economic growth and the state as its principal agent, one of its central concerns of development policy is to articulate the state’s role in the development of state-market relationships (Sen, 1999).

This chapter has provided a range of theoretical and conceptual considerations of the role of international development in defining and responding to crises of the state; it is these considerations that undergird and guide the current study. The chapter has embedded the development discourse in the scholarly writings of Ferguson (1990), Escobar (1994; 1995), Rist (1997) and Mosse (2005), and employed a Foucauldian discourse analytic framework. Together with reference to indigenous knowledge structures, the development discourse has been contextualised through the international development response to the HIV/AIDS epidemic.

# Chapter 4: AIDS, Governance and Civil Society

This chapter discusses the various dimensions of governance policy and practice with regard to the response to the HIV/AIDS epidemic in South Africa, paying particular attention to the interplay between civil society and the state. A literature-informed discussion of the concept of governance and the various ways in which it plays out in economic and social development policy and practice is presented.

During the last decade, South Africa has experienced a discernible shift in the politics and practice of governance with regard to the HIV/AIDS epidemic. In particular, the shifting roles of the state, government-sponsored initiatives, international donors, and civil society. These shifting roles have received growing attention from both academics and the media at a national and international level.

## 4.1 The Concept of Governance: Theory and Practice

There is no universally accepted and agreed upon definition of governance, in spite of the fact that the concept of governance has been studied by social scientists for a long period of time. It has been variously described, often in vague terms, and embodies varying theoretical constructs, many of which are contradictory one to the other (Pierre and Peters, 2000; Turner and Hulme, 1997). Contradictions and vagueness aside, governance is generally acknowledged to be concerned with a particular political system, and is based on the tension between the steering and coordinating functions of the policy decision-making process. Disagreements about governance in a political context are typically over *who* is doing the steering and to what extent various actors are involved in the steering process.

Pierre and Peters' seminal studies on the mechanisms of governance examined government's capacity to steer the broader society through the policymaking and

implementation processes (2000; 2002). They argue for an historical lens through which to examine government's role in governance structures and suggest that studying the interdependence between public and private sectors is critical to this examination. They further argue that assumptions about hierarchical governance structures with government at the top, controlling and regulating private sector activities, are not based on valid assumptions. Government's capacity to unilaterally steer society is substantially constrained by participatory mechanisms such as social movements, community-based advocacy organizations, and the pressure exerted by private sector interests (Pierre and Peters, 2000).

They identify two common approaches to studying governance, through *structure* and *process*. The latter is a dynamic view of governance that results from the natural outcome of interactions between political and social actors. On the other hand, the structuralist approach views governance as comprised of *hierarchies*, *networks*, *markets,* and *communities*.

Much of the contemporary literature on governance rejects the hierarchical approach when studying the politics and practical application of governance principles. Western societies notion of governance is increasingly characterized by horizontal relationships and the roles played by influential networks and other powerful coalitions that participate in shaping public policy (Bell and Hindminor, 2009; Sorensen and Torfing, 2008 as quoted in Bell and Hindminor, 2009). This perspective is predicated on the belief that government is incapable of steering policy independent of non-governmental vested interests.

It has been suggested that networks consist of small interest groups or groups working with larger collective interests. Further, that the state uses networks as a means to engage civic society in the policy-making process. Policy networks comprise both public and private actors that together are capable of challenging state power and "facilitate coordination of public and private interests and

resources and, in that respect, enhance efficiency in the implementation of public policy" (Pierre and Peters, 2000). They argue that despite the increasingly important role of these horizontal relations, hierarchical relationships still have a powerful influence on defining relationships between private institutions and government.

An alternative theory posited by Pierre and Powers is that *markets* are the central mechanism for activating governance processes. In this theoretical construct, citizens participate in governance through exercising power as consumers.

The final alternative construct put forth by Pierre and Peters is that *communities* are the primary mechanism of governance (2000). In this scenario, communities are considered more capable of finding solutions to their problems and organizing local activities as opposed to central government. As a result, they argue that neither the state nor markets are the appropriate mechanism of governance, but rather local communities where policy is put into action. This communitarian approach to governance is built on community participation, consensus, and reflective of the larger collective interests of community (Pierre and Peters, 2000).

In a later manuscript published by Pierre and Powers (2002), they argue that focusing on structure alone, i.e., hierarchies, networks, markets and community, misses the importance of the interactions between these structures; that is, the *processes* involved in structural interactions. Governance is thus understood as a dynamic process operating between actors in political and social spheres. This way of understanding governance is important as "governance is not so much about structure, but more about interactions among structures and individuals" (Pierre and Peters, 2002). Governance can therefore be considered dynamic as the actors involved are likely to vary across time and space. It is therefore important to take into account the context in which actors are operating.

In spite of the state-centric approaches used to explain the apparatus of governance structures and processes, I argue that governance should not be restricted to state operations and institutions, but rather that it is a mechanism that crosses traditional boundaries of public and private spheres. In this view, governance is a dynamic process of formal and informal social and political structures involving the interactions of multiple actors from the state to markets and civil society. As such, actors can be government agency officials, politicians, NGOs, social movements, large enterprises, and small community-based organisations (Millstein, 2007; Mogale, 2003).

The operating assumption underpinning this study is that governance does not serve solely a 'steering' function, but rather it is a dynamic political phenomenon wherein negotiation and compromise define its outcomes. Therefore it is necessary to study the roles played by various actors and their relationships to one other and the partnerships and cleavages that form as a result of these interactions.

### 4.2 The Politics of Governance

Milstein suggests that "governance is at the same time argued to be fundamentally a political process and has everything to do with politics" (Millstein 2007: 51). He further argues that although institutional reforms typically occur at the community level, those who are steering the reforms often ignore the politics of local governance. Such politics are typically how "transformations interact with local social and political dynamics" (Millstein, 2007: 16).

The politics of governance can take various forms, depending on the context in which it evolves and influence that is exerted from above and below. Political structures are often put into place on a national or international level by administrative reforms brought about by eternal demands for a democratization of the processes of governance. Simultaneously, local governance policies can

be challenged by mobilizing human rights campaigns to ensure that participatory governance processes are established locally (Friedman, 2006; Millstein, 2007).

To this end, the decentralization of power and decision-making to lower levels of government has been promoted as a way to increase government efficiency, ensure accountability, and maximize civic participation (Heller, 2001).

Turner and Hulme (1997) identified centralized decision-making as a major obstacle to economic and social development for countries in the south because central governments are geographically and socially isolated from the communities that are the beneficiaries of development projects. They argue that decentralizing power to local governments better facilitates alignment of decision-making with local preferences. This argument assumes that in order to achieve a sustainable democratic process, civil society participation is critical (Heller, 2001). Many, if not most, national governments have adopted a range of governance practices that attempt to distribute authority between the state and decentralized governmental entities (Turner and Hulme, 1997). This is the case in South Africa where local governments have become central players in post-apartheid reconstruction and economic development efforts.

Decentralization of governance in South Africa is aimed at locating development initiatives with local authorities to encourage civil society to actively engage in the policy decision-making process (May, 2001; Mhone and Edigheji, 2003). Participatory governance has strong roots in South Africa as a result of the struggle against apartheid policies wherein the majority of black South Africans were excluded from formal channels of participation in the policy decision-making process (Friedman, 2006). The end of apartheid and the democratization of South Africa opened up space and brought new opportunities for civil society to influence and participate in public policy−whether through the constitutional court or direct engagement with the agencies of government (Friedman and Mottair, 2006).

South Africa is characterized by three distinct yet interdependent levels of government, national, provincial and municipalities. There are presently 284 municipalities in South Africa. These recently demarcated entities amalgamate 843 racialized structures and incorporate urban and rural areas into single (often much larger) municipal systems (Atkinson, 2003). According to Naudé this change in size (determined by the Demarcation Act of 1999) was primarily driven by an economy of scale imperative (2003). Municipalities are split into six category A municipalities (metropolitan councils), 231 category B municipalities (local municipal areas), and 47 category C municipalities (district councils).The latter governs a local government district. District municipalities encompass a number of local municipalities (category B), as well as district management areas (DMAs). The latter areas are mostly rural not directly governed by a local municipality. Metropolitan Councils (Category A municipalities) govern in the six metropolitan areas and are responsible for ensuring a good quality of life for citizens and for promoting sustainable social and economic development. Even though many programmes have been launched in these metropolitan areas in the recent past, few projects have been successful and sustained. Not surprisingly, local governments are typically constrained by competing demands for human and financial resources. As a result, although local responses to HIV/AIDS are viewed as an important component in the fight against the disease, little has been done to accommodate the challenges local governments face in dealing with such a formidable public health problem.

Camay and Gordon caution that decentralization alone does not ensure participatory governance,

> "Decentralisation of governance in and of itself does not ensure more popular participation or government accountability. Regardless of the dictates of the Constitution and legislation, much also depends on the tone set by government officials and politicians at each level of government in terms of their openness to consultation with the public…Successful decentralization also depends on the

> government's capacity and willingness to really listen to the views of these stakeholders and take them into account" (Camay and Gordon, 2004).

It has been argued that public-private partnerships open the way for individuals to collaborate in partnership with the state, private markets, and civil society thus engaging in the practice and politics of participatory governance. The emphasis on the role of partnerships in good governance is often associated with a neo-liberal discourse wherein public-private partnerships are central to achieving progressive economic and social development goals. This being said, the literature on public-private partnerships often ignores the conflict and power struggles that can arise between groups with divergent, and sometimes conflicting goals (Millstein, 2007).

Even when opportunities for participation are opened up, the extent to which participatory governance occurs depends on both context and existing power relationships. Participatory governance tools may be unavailable to parts of the population while being used actively by political elites to promote their own agenda. Participatory governance is more available to citizens with the capacity to organize, and while some social activists can easily mobilize formal and informal networks, others lack the capacity or know-how to do so. Hence, it has been noted that promoting participatory governance can unknowingly exacerbate unequal power relations between civil society and interest groups at the expense of the weaker partner (Friedman, 2006; Millstein, 2007; Mogale, 2003).

**4.3 The State-Civil Society Discourse**

Migdal (2001) rejects the notion of a dichotomy of interests between the state and civil society in issues of governance. Instead, he argues for a more nuanced understanding of how social transformation occurs in what he calls the "state-in-society". He argues that there is a constant and on-going struggle over social

control in every society and that there are multiple examples of "domination"[29] that can be observed. In this view, the state is not only a force for responsible for transformational policies, but rather struggles for domination are waged between the state and other powerful actors in society. In other words, the structure and practice of governance is the result of interactions between public and private forces. This interaction leads to constant change in the structure, goals, and rules of the governance process.

> "Like any other group or organization, the state is constructed and reconstructed, invented and reinvented, through its interaction as a whole and of its parts with others. It is not a fixed entity, its organization, goals, means, partners, and operative rules change as it allies with and opposes others inside and outside its territory" (Migdal, 2001).

He would argue that it is misleading to consider the state as a representation of the people simply because of its geographic imperative, but rather the state has a dual function of operating as a single actor while at the same time cooperating with and sharing influence and power with a range of public and private actors (Migdal, 2001).

The state does holds a central position in negotiating with other states and countries and has a significant governance role in policymaking in the most remote areas of its geographic boundaries in the provision of health care services, public schools, roads and sanitation. In short, the state does play a major role in shaping societal structures while civil society plays a substantial role in influencing how the state shapes these structures.

### 4.4 Conceptualising Civil Society

"For more than a decade, the notion of civil society has held a central sway in official, academic and popular discourse about development, democracy and

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[29] By 'domination' Migdal refers to the ability to gain obedience through the power of command (2001).

governance in the world" (Habib and Kotze, 2003: 51). Civil society can be defined as "the organized expression of various interests and values operating in the triangular space between the family, state and the market" (Ballard et al., 2006: 76). Civil society is a heterogenic space when recognizing the plurality of state-civil society relations (Habib, 2003; Habib and Kotze, 2003).

Habib and Kotze make a distinction between civil society organisations that have taken an oppositional stance with regard to the state and those that engage in collaborative partnerships with the state, therefore "working within the system" (2003). These two approaches have been referred to as 'the *politics of opposition*' and '*the politics of engagement*'. The latter type are typically formal, larger, and service-delivery oriented NGOs. The former are generally classified as social movements defined as " politically and/or socially directed collectives, often involving multiple organizations and networks, focused on changing one or more elements of the social, political and economic system within which they are located" (Ballard et al., 2006). Habib argues that ensuring the right of access to public benefits in marginalised communities requires combining the politics of engagement with politics of opposition (Habib, 2003; Habib and Kotze, 2003).

**4.5 HIV/AIDS Governance Policies and Practice in South Africa**

The HIV/AIDS epidemic has been a significant challenge to participatory governance in South Africa. Both the state and civil society have been challenged to find ways to appropriately and humanely deal with this public health crisis in the face of other compelling social and economic issues facing South Africa in the post-apartheid era. The private and public response to HIV/AIDS is intertwined with participatory governance structures in a number of important ways, particularly when looking at the political dimensions of governance.

The HIV/AIDS epidemic has threatened participatory governance because of decreasing citizen support for the government's response to the crisis. Barnett

and Whiteside (2006) argue that people who are infected or affected by HIV/AIDS are less interested in how they are governed and more focused on government's response to the burden of the disease where families and communities are overwhelmed by the responsibilities of care-giving and the disintegration of their communities. As a result, with growing numbers of people affected by the disease, lower levels of participation in elections and the erosion of other participatory activities have resulted (Strand et al., 2005). A government that is perceived to be unable to respond in a timely manner, or that lacks perceived leadership is judged by the electorate as ineffectual and faces a crisis of legitimacy (Jones, 2004c). As this study demonstrates, the response of South Africa's national government and its leaders have repeatedly faced a crisis of legitimacy since the HIV/AIDS epidemic was first acknowledged.

Strand et al. argue that a politically appropriate and socially acceptable response to the HIV/AIDS epidemic must recognize that HIV/AIDS is first and foremost an issue of economic and social development that requires sufficient institutional capacity, adequate financial resources, and the involvement of all key stakeholders at every stage of government's response in the design, implementation, monitoring, and evaluation of the response (Strand et al., 2005). "A good governance response to HIV/AIDS is one that is permeated by an awareness of the epidemic and practical responses implemented successfully across all sectors of society" (Strand et al., 2005: 20).

If we assume a multi-sectorial response is needed, prevention strategies and preferred treatment options must encompass a more holistic response, they must also include social and economic development projects. Lacking this more holistic approach puts the South African government to the test (Govere, 2005). It has been well-established that the HIV/AIDS epidemic is rooted in the dire poverty conditions experienced by much of the black South African population, even 20 years after the end of apartheid. The interplay between poverty and

disease is well known, and taken together, they form a vicious circle from which the country has yet to emerge.

The HIV/AIDS epidemic in South Africa fuels continually discrimination, stigma, and unequal access to effective treatment options (UNAIDS, UNFPA and UNIFEM, 2004).

> "As the levels of sickness and deaths escalate, with AIDS becoming the biggest cause of death of 15-49 year olds in South Africa, the perception of limited government response to tackling stigma, in addition to the hardening position on opposition to treatment, are perceived by many in civil society and the medical profession as wholly inadequate and a violation of constitutional rights" (Heywood as quoted in Jones, 2004).

The United Nations Development Programme (UNDP) reported in 2006 that success in tackling the HIV/AIDS epidemic in South Africa will depend on how the overall national response is governed, managed and coordinated. Further, that it will require strong leadership at all levels of government and must include the dynamic interaction between government and civil society (UNDP, 2006).

**4.6 The Politics of AIDS: The State and Civil Society**

The growing interest and support of civil society organizations in Africa arose during the 90s because of growing access problems to basic services to combat the HIV/AIDS epidemic as delivered by the state and its agencies. Specific contextual factors included: the policy aims of civil society including objectives and strategies; the role of international donor-funders; and the state's agenda, or lack thereof. A seminal example of the role of civic society in shaping policy, and the subject of this thesis, is the symbiotic relationship that has developed between the state and the Treatment Action Campaign (TAC), an activist organization.

In the Eastern Cape Province, the TAC formed in 2003 in response to what was perceived to be a lack of appropriate government response to the rapidly growing

incidence of HIV/AIDS in South Africa. Its success as an activist organization/social movement can be demonstrated in its present working partnerships with twenty-two partner organizations to support the agenda of its treatment programme priorities. Its partner organizations include the Eastern Cape AIDS Council (ECAC), Eastern Cape NGO Coalition (ECNGOC), and other local NGOs. In addition, the TAC partners with government agency staff including the Departments of Health, Education, Correctional Services, and Social Development as well as the South African Police Service by providing training to these governmental agencies. The TAC can be viewed as an example of a participatory governance strategy that has successfully bridge the territorial gaps between the public and private sectors. More importantly, it represents a social movement organization that has successfully had a significant influence on government policy and agenda-setting.

The relationships that form between civil society organizations and the state are quite dependent on the political system in power and how civil society perceives it. "Where [a] political system is hostile to social movements, the relationship will be adversarial – relations between the apartheid state and resistance organizations are an example" (Ballard et al., 2006).

In the case of the TAC, its relationship with the government can be characterized as both co-operative and conflictual. The TAC recognizes that an alliance with the state is possible and that cooperation and confrontation can be complementary strategies (Friedman and Mottiar, 2004). The national and provincial governments, both in the past and presently, have displayed little enthusiasm for working in partnership with the TAC, in spite of national departments utilizing its educational services. For example, "the TAC was initially excluded from the South Africa National AIDS Council (SANAC) established by the government" (Friedman and Mottiar, 2004: 33).

In the Eastern Cape, the TAC is still not a member of the Eastern Cape AIDS Council (ECAC), a provincial government body, or the Eastern Cape NGO Coalition, an Eastern Cape mother board which works in partnership with ECAC.

National and provincial governments strive to maintain control over HIV/AIDS policy and programs which has made the relationship between the TAC and the government conflictual at times. The TAC perceives its role is not to help the government achieve its objectives but rather to put pressure on governmental agencies and their HIV/AIDS policies that TAC deems to be inequitable or ill-advised.

> "TAC's mode of engagement with government, in which co-operation and conflict are intertwined, is not simply born of convenience. It does also recognize that, while the power of democratic governments could be used against the grassroots, they are elected and so cannot be dismissed as 'enemies of the people'" (Ballard et al., 2006: 81).

While the TAC's approach represents a complicated relationship, it has employed this approach in which co-operation and conflict are intertwined, to achieve its goal of representing the medically disenfranchised in civil society.

### 4.7 The Role of NGOs in Participatory Governance

Governance literature has increasingly scrutinized the influence that international donors play as well as the roles of the NGOs with whom they partner in pursuit of their development goals. Jones has noted that some international approaches to HIV/AIDS assistance have actually subverted the ideal of democratic governance principles that open opportunities for civic engagement by assuming an elitist posture;

> "Too often… the current development orthodoxy of human rights, good governance and democratization, with aid at the vanguard, remain as elite negotiations with minimal institutional reforms. What is desperately required to make the governance of HIV/AIDS

> interventions more effective are new, alternative spaces and political channels for effective participation in decision-making and coordination" (Jones, 2004a: 32).

It has been demonstrated that in a number of cases, international donors have promoted their home country's policy agenda with regard to HIV/AIDS funding to the detriment of a recipient country's environmental circumstances wherein aid decisions have not adequately take into account local conditions or cultural norms (Jones, 2004b; Seckinelgin, 2004). Seckinelgin further argues that to the extent HIV/AIDS funding policies and priorities are set at an international level, national and sub-national levels of government in recipient countries are significantly constrained in their ability to meaningfully participate in the policymaking and priority-setting process (Seckinelgin, 2004: 296).

Theoretical constructs about the role of NGOs and their relationships with international donors are important in understanding their influence on participatory governance. Further, an understanding of the donor-recipient relationship is important to consider when studying the role of NGOs in the governance process.

The shift towards neo-liberal economic strategies brought about by globalization has resulted in constraining the role of local governments and the promotion of private sector influence. International financial institutions increasingly depend on private NGOs to play a central role in governance activities with the goal of supporting NGOs in pursuit of enhancing state efficiency and legitimacy. It is a commonly held assumption that to ensure democratic development processes occur, the mobilization of civil society is required (Mercer, 2002; Pearce, 1993).

It has been argued that the form governance takes cannot be explained just by changing the role and dominance of the state, but by increasing the role and influence of NGO actors (Millstein, 2007). There is an on-going debate about whether NGOs strengthen or weaken the state and civil society. The dominant

liberal view is that civil society organizations in the form of NGOs provide the link between the state and grassroots communities. Non-profit NGOs are assumed to be embedded in and reflect the needs of the community, thus holding the government accountable (Mercer, 2002).

NGOs are assumed to represent the poor and marginalised groups in society. However, a growing literature questions the role of NGOs as representatives of civil society (Mercer, 2002; Clarke, 1991; 1995; 1998). From my personal experience working in a number of NGOs as well as those of respected scholars, there is a need to better understand the potential that the conflicting interests and inter-organisational power struggles that occur within and between NGOs can negatively impact the over-arching goals of civil society (Habib and Kotze, 2003; Mercer, 2002; Sabatini, 2002).

Because there is spatial and temporal diversity among NGOs, and the fact that civil society might have fragmented and conflictual goals, there is need to carefully scrutinize the context in which NGOs operate. For example, an NGO may be leading a strong leader who does not provide space and opportunity for staff and the community to meaningfully participate in decision-making processes.

NGOs do not necessarily represent or have an understanding of the marginalised populations they are funded to serve as is generally assumed by many international donors. Particularly in case where donors accelerate funding opportunities, pursuing dollars compromises the accountability of NGOs that become more focused on additional funding than their obligation to the communities they serve. Accountability is directed upwards to donors as opposed to downward to the community (Habib and Kotze, 2002; Mercer, 2002; Sabatini, 2002). Examining the internal organization of NGOs can help in better understanding the legitimate role they play in furthering the goals of civil society, including their ability to have a sustained impact on civil society's social and

economic development priorities. (Mercer, 2002) In sum, there needs to be an on-going, critical evaluation of factors such as leadership, commitment to community goals and preferences, and the relevance of programmes to community need, to assess their role as agents of civil society.

Whether through social activism or the setting of program priorities, NGOs influence policy-making and participate in governance activities. According to Chopra and Ford (2005), NGOs have the potential to create spaces where people can develop action on community issues. As non-governmental organizations, they can facilitate and improve communication channels between the community and government. They also create space where people who do not normally communicate with one another can participate in developing a common agenda in a safe space (Chopra and Ford, 2005).

### 4.8 The Donor-Recipient Discourse

"As an encounter between individuals with differing interests, resources and power, aid relationships are conflictual" (Schneider and Gilson, 1999: 36). The success of donor-recipient relations, i.e., aid partnerships, depends on the ability of both parties to manage conflict. Donors and recipients enter into partnerships that are shaped by the socio-political and economic context of their respective countries, thus creating a potential clash in interests (Schneider and Gilson, 1999). Quite often the donor-recipient discourse is characterized by differing interests and expectations and coupled with an unequal balance of resources and power.

When donors fund a development project, they are under pressure to show the product of their aid. The programme in question is expected to produce concrete outcomes from the investment. In other words, every investment should be a showcase of the donor's beneficence. Further, there is often competition between donors in a particular development space as to which is promoting the better policies and achieving the greater outcomes.

In countries like South Africa, limited domestic funding has resulted in CSOs increasingly dependent on international donors (Sabatini, 2002). “The reality is that donors wield enormous power over the political, economic development and direction of recipient organizations and countries” (Habib and Kotze, 2003: 62). This dependence on international donors has the practical effect of donors deciding which civil society organisations survive and thrive and those that do not. It is therefore common for NGOs to design their programmes with the donor’s priorities in mind. In other words, the way that donors define a development issue is often the way civil society organisations define the issue if they want to get financial or technical support from the donor. The parties then engage in trade-offs and compromises, most often with the donor’s priorities intact (Habib and Kotze, 2003).

One strategy intended to equalize this imbalance of power has been to encourage partnerships between donors and NGO recipients. Such partnerships are intended to create more horizontal relations to balance previous unequal power relations between partnerships (Jones, 2004a). According to Jones, the view of donors as experts prevails which has the practical effect of stifling efforts to rectify the power imbalance and curtailing programme ownership by the CSOs of foreign aid-funded initiatives.

**4.9 NGOs in a Geopolitical Context**

Northern hemisphere NGOs (NNGOs) endured a 'crisis of identity' in the 1970s and 80s (Smillie, 1994) with much discussion ensuing about their appropriate role in international development efforts. An increasing emphasis on 'bridge-building' roles and involvement in capacity-building activities with Southern NGOs (SNGOs) was posited (Brown, 1990). Partnerships rose to prominence as fulfilling the dual bridge- and capacity-building functions. North-South partnerships would make it possible to tailor development projects to local needs and concerns, and concomitantly leverage the development expertise and

resources of the Northern partners. As was noted by USAID, widespread capacity building would enhance the ability of Southern partners to deliver and expand their services while increasing efficiency and legitimacy with local governments (USAID, 1997).

Although the concept of partnership was influenced by ideological notions of international solidarity (Fowler, 1997; Murphy, 1991), current North-South partnerships are generally regarded as enabling more efficient use of scarce resources, increasing sustainability, and enhancing beneficiary participation in local development projects. It is believed that the creative synergy resulting from partnership will produce results that the individual partners could not achieve without the collaboration (Brown, 1990). The advantages of cross-sectorial, cross-national partnerships were first broadly discussed in a U.S. and European social policy context in the 1980s (Billis, 1993; Mackintosh, 1992). A number of experts, practitioners, and observers have identified the necessary elements that should be present for a successful cross-sector, cross-national partnership. Among these:

- Mutual trust, complementary strengths, reciprocal accountability, joint decision-making, and a two-way exchange of information (Postma, 1994).
- Clearly articulated goals, equitable distribution of costs and benefits, performance indicators, mechanisms to measure and monitor performance, clear delineation of responsibilities and a process for adjudicating disputes (USAID, 1997).
- Shared perceptions and a mutuality with give-and-take (Tandon, 1990).
- Mutual support and constructive advocacy (Murphy, 1991).
- Transparency with regard to financial matters, long-term commitment to working together, and recognition of other partnerships (Campbell, 1988).

### 4.10 Organisational Theory and NGO-Donor Relations

Organisational theory has been used effectively to examine NGO-donor relationships (Lewis et al., 2003). Hudock (1995) and Yanacopulos (2005) used

organisational theory to describe the vulnerabilities of South NGOs (SNGOs) due to their lack of resources, thus made them dependent on donor funding, and the resultant effect on their internal operations.

According to Pfeffer and Salancik (1978), in order to understand organizational behavior it is first necessary to understand the environments in which they are embedded and operate. These environments include other organizations within their sector as well as other stakeholders, associations, alliances, government, and the social-legal structures that regulate the relationships between these players.

In order to survive, organizations must acquire and maintain resources through interacting with other players and organizations. These interactions will in turn shape the activities they pursue and the outcomes they achieve. In a resource rich environment, the interdependence between organizations is minimized, while environments with resource scarcity and greater uncertainty the need to cooperate is increased, but so is the need to develop strategies to compete for limited resources (Pfeffer and Salancik, 1978).

Asymmetrical relationships often force competing organizations to choose between conflicting goals, where satisfying one organization's demands may come at the expense of another. Organizations are vulnerable to the extent that they become dependent on particular types of exchange in order to operate. According to Pfeffer and Salancik, organizational dependency is defined as the critical importance of a given resource and the extent to which it is controlled by a relatively small number of other organizations (1978). Dependency, then, is a measure of the extent to which one organization is perceived to be critical to the survival of another (Pfeffer and Salancik, 1978).

### 4.11 NGOs, International Donors, and the Dynamics of Dependency

Organisational theory provides a plausible rationale for the organizational changes that occur within NGOs as a result of the asymmetrical power dynamics they face with donor organisations. According to Wallace et al (2006), coercion and compliance are crucial concepts in helping understand the relational dynamics between NGOs and their foreign donors. Donor agencies provide funding and other resources, and are therefore in a position of dominance to set the agenda and conditions for funding. As the holders of valuable resources on which NGOs are dependent, international donors are in a position of power that allows them to put conditions on how aid is used and programs are implemented (Chambers and Pettit, 2004).

The financial instability in many recipient countries makes salaried employment at an NGO a much greater opportunity than it would otherwise, therefore securing grants becomes a powerful force in under-resourced organizations (Henderson, 2002; Petras and Veltmeyer, 2001). NGOs with a social justice agenda, from humanitarian relief to equitable social and economic development projects are particularly vulnerable.

Based on the arguments and examples laid out in this chapter, it is apparent that NGOs play a pivotal role in the politics and practice of participatory governance. NGO involvement illustrates that participatory governance is a complex undertaking. Governance policy and practice is a well-suited framework for analysing international funded development aid in an economic and social arena such as HIV/AIDS policy. The critical importance of the politics of governance is the underlying theme of the analysis in this study.

# Chapter 5: International Donors as Agents of Strategic Translation

> "In June of this year (2003), President George W Bush informed American NGO leaders that they were in fact "an arm" of the U.S. Government – and that they had an important job to promote U.S. interests in Afghanistan and Iraq. Furthermore, NGOs receiving funding from the U.S. Government were not to speak to reporters or publicly express critical opinions of U.S. foreign policy" (Klein, 2003).

In this chapter I discuss the intermediary role played by the United State President's Emergency Plan for AIDS Relief (PEPFAR)[30] and its role in the strategic translation of HIV/AIDS global policy. The aim of the chapter is to illustrate how PEPFAR funding was strategically positioned as the largest global HIV/AIDS donor in the battle against HIV/AIDS. This positioning included the promotion of pharmaceuticals, namely antiretroviral (ARV) medications, as the primary intervention in the fight against the HIV/AIDS epidemic in African countries.

This emphasis on a pharmaceutical approach that was promoted by PEPFAR funding has had its detractors as noted by Easterly;

> "The advocates of treatment stress the universal human right for HIV-positive patients to have access to life-saving health care, no matter what the cost. This is great ideal, but a utopian one. There are also other ideals – first of all, prevention of further spread of AIDS. And what about the universal right for health care for killer diseases, freedom from starvation, and access to clean water? Who chose the human right universal treatment of AIDS over the other human rights?" (Easterly, 2006)

[30] The United States President's Emergency Plan for AIDS Relief (PEPFAR), which is by far the largest global initiative focused on HIV/AIDS was launched in 2003, and it represents the largest foreign assistance initiated by any nation in history to combat a single disease (Kates et al., 2008).[30] "PEPFAR represents an unparalleled national commitment to combat a single disease and has had tremendous potential to help tackle HIV/AIDS through its own resources and influence" (Ghanotakis et al., 2009). Since the launch of PEPFAR a decade ago, South Africa has and continues to receive more PEPFAR resources than any other nation with cumulative funding totalling to over US$3.7 billion.

In this chapter, I will discuss the ways in which PEPFAR, as the world's largest HIV/AIDS donor, strategically positioned itself as what Wiebe Nauta (1999) calls a strategic translator of HIV/AIDS policy and how PEPFAR-funded monitoring and evaluation systems serve to perpetuate the pivotal role of global NGOs in reinforcing these policies.

### 5.1 Overview of the PEPFAR Initiative

> "Many of us who are active in the fight_against HIV in Africa, where AIDS has hit the hardest and where most PEPFAR funds have been spent, watched with disappointment in the early days of PEPFAR as the Bush administration redefined the "ABC" approach as a preference for abstinence-until-marriage programming; as NGOs doing good work lost their funding as a result of the prostitution pledge; and as foreign governments, implementing agencies, and USAID program officers exhibited a stunning disregard for the needs of men who have sex with men and other HIV-vulnerable groups" (Evertz, 2010).

In January 2003, then President George W. Bush called for the United States to commit $15 billion over five years to address the international AIDS epidemic through the PEPFAR (Dietrich, 2010). In May 2007, President Bush called for the reauthorization of PEPFAR with a doubling of funding, asking Congress to authorize an additional $30 billion over the following five years (Dietrich, 2010). With such a large figure before the Congress, the issue of US leadership in the fight against the HIV/AIDS epidemic took on unprecedented proportion of commitment to fighting the epidemic (Dietrich, 2010), PEPFAR's goal was to prevent an estimated 7 million new cases of AIDS, treat 2 million currently infected people with AZT drugs, and provide known effective treatment to millions of people infected with AIDS as well as children orphaned by HIV/AIDS.[31]

The $15 billion commitment included $5 billion for existing bilateral programs throughout the world, $1 billion to the UN Fund ($200 million per year), and $9

[31] "State of the Union, 2003," available at: www.whitehouse.gov/news/releases/2003/01/20030128-19.html.

billion for new programs in fourteen target countries in Africa and the Caribbean (Evertz, 2010). The Bush Administration established specific numeric targets for prevention, treatment, and care. Prevention would include programs that addressed sexual transmission following the Uganda ABC model.[32] Treatment represented roughly half of all PEPFAR spending.[33]

Although unprecedented in scale and scope, the PEPFAR funding announcement in 2003 was not the first US initiative focused on the international AIDS pandemic (Dietrich, 2010). The magnitude of the AIDS crisis became apparent to US officials in the 1980s, and small amounts of funding were soon allocated to efforts to address it (Dietrich, 2010). In 1996, the United States supported the creation of a UN program to coordinate global AIDS efforts. In subsequent years, the Clinton Administration increased attention to the HIV/AIDS crisis. In 2000, a bill signed by President Clinton authorized $150 million to fight AIDS that was administered by the World Bank and an additional $300 million for bilateral programs (Kohn, 2005). In the spring of 2001, UN Secretary General Kofi Annan put new pressure on world governments by proposing the creation of a Global Fund to fight AIDS, Tuberculosis, and Malaria (Kohn, 2005). On May 27, 2001, President Bush announced that the United States would make a founding contribution of $200 million to the Fund and pledged to add more if the programs proved effective (Kohn, 2005; Evertz, 2010).

The United States Agency for International Development (USAID) Administrator Andrew Natsios argued for preventive measures and against sending antiretroviral drugs to African countries because of their lack of an adequate health care infrastructure and the inability of Africans to adhere to a complicated treatment regimen (Kohn, 2005; Evertz, 2010).

[32] David Brown. ‘‘Group Awarded AIDS grant despite negative appraisal the ABC of HIV Prevention”, available at www.avert.org/abc-hiv.htm.
[33] “PEPFAR Funding: How is the Money Spent?” available at www.avert.org/pepfarfunding.htm.

### 5.2 The PEPFAR funding formula

More significant than the ABC[34] focus was the strict language contained in the authorizing legislation that designated how PEPFAR funding could be allocated (Kohn, 2005; Evertz, 2010). The law required that 55 percent of funds go to HIV/AIDS treatment, 20 percent to prevention initiatives, 15 percent to palliative care, and 10 percent to support for orphans and vulnerable children.[35] In addition, one-third of the prevention funding was earmarked for abstinence-until-marriage programs, leaving all other prevention programs, including condom promotion, safe interveneous (IV) drug use, safe sex practices, and nonsexual transmission prevention, to divide up the rest of the prevention dollars (Kohn, 2005).

### 5.3 The economic interests associated with HIV/AIDS policy

While international HIV/AIDS programs are generally described in humanitarian terms, they also represent the interests of big business (Pisani, 2008). The overseas distribution of U.S. financial assistance amounts to hundreds of millions of dollars per year. Increased spending on prevention equates with major orders for condom distributors; and more importantly, the emphasis on AZT drug treatment has huge profit implications for the pharmaceutical industry.

One early indicator these interests was the creation of two lobby groups, the Corporate Council on Africa's Task Force on AIDS, and the Coalition for AIDS Relief in Africa, which brought together major pharmaceutical companies, such as Bristol-Myers Squibb, Abbott Laboratories, Pfizer, and others to lobby Congress in support of PEPFAR funding (Pisani, 2008).

With the initiation of PEPFAR funding, the Bush Administration held that monies could only be spent on name-brand drugs, thus protecting patent rights and assuring drug quality. The Bush Administration retained the Clinton-era policy

[34] "The ABC of HIV Prevention," available at www.avert.org/abc-hiv.htm; Foreign Policy in Focus, "The Flawed ABCs of PEPFAR."; David Kohn; "More HIV Funds to Promote Abstinence: Researchers Call Policy Misguided" *The Baltimore Sun*, December 10, 2005 available at: www.actupny.org/reports/bush_abstinencefunding.html

[35] "PEPFAR Funding: How is the Money Spent?" available at www.avert.org/pepfarfunding.html

that allowed drug companies in India and Brazil to produce generic versions of US-patented drugs, but stipulated that these countries were not to export these drugs to other countries. Interestingly during this period, President Bush appointed the former chairman of Eli Lilly and Company, Randall Tobias, who had no previous AIDS policy experience or experience with African politics, to serve as U.S. Global AIDS Coordinator. While traveling in South Africa in 2004, Tobias commented about generic drugs by stating that, ‘‘maybe these drugs are safe and effective. Maybe these drugs are, in fact, exact duplicates of research-based drugs. Maybe they aren't. Nobody really knows.’’ [36]

Others argued strongly that generics were safe, given that they had been approved by the World Health Organization's (WHO) prequalification program and were being distributed by several national governments, international NGOs, and other groups financed by the UN Fund. These individuals argued that generic drugs should be considered a crucial part of any major treatment strategy because their cost was a third or less of US brand named drugs. It was further argued that patient compliance with drug regimens could be increased by using three-in-one combination pills that were not available from any US manufacturer at the time.

When President Bush signed into law the United States Leadership against HIV/AIDS, Tuberculosis, and Malaria Act of 2003, also known as the Global AIDS Act, he created "the largest commitment by any nation to combat a single disease in human history."[37] This legislation authorized PEPFAR and committed more than $25 billion to the fight against global AIDS since 2003 (Kohn, 2005; Evertz, 2010).

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[36] Randall Tobias, as quoted in Nina Siegal, ‘‘No Experience Necessary: A Profile of Bush's AIDS Czar’’ Progressive 68, no. 11 (November 2004).

[37] The Henry J. Kaiser Family Foundation. (2008). "President Bush Signs PEPFAR Reauthorization Bill" available at www.kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=53609

PEPFAR has brought life-prolonging antiretroviral drug treatment to more than 2.1 million people and provided HIV counselling and testing to nearly 47 million more. It has contributed to the care of more than 4 million orphans and vulnerable children, and has made services available to nearly 1.2 million HIV-positive pregnant women to prevent mother-to-child HIV transmission.[38] PEPFAR funds have been committed to work in partnership with host nations worldwide to support treatment of at least 3 million people by 2013, prevent 12 million new infections and care for 12 million people, including 5 million orphans and vulnerable children.[39]

### 5.4 From Direct Support to Technical Assistance

NGOs in South Africa experienced first-hand the effect of PEPFAR's shift from support of direct services, i.e., ARV treatment, to the provision of technical assistance. PEPFAR supported clinics and NGOs either flat-lined, shut down, or redirected patients to overburdened government health facilities.

When I resigned as the Monitoring and Evaluation Officer and Project Coordinator of Sophumelela Clinic Incorporated (SCI) in April 2012, this local faith-based ARV clinic was closing down while at the same time applying for PEPFAR technical assistance funding.

PEPFAR's shift in HIV/AIDS programme funding priorities posed enormous challenges for South Africa as the largest recipient of PEPFAR grants. Local NGOs quickly positioned and realigned themselves to PEPFAR's new funding focus area of technical assistance and health systems strengthening to ensure the continuance of receiving millions of US dollars.

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[38] U.N. Integrated Regional Information Networks. (2009). "A new and improved PEPFAR under Obama?" available at www.irinnews.org/report.aspx?ReportID=82494

[39] U.S. Embassy Kampala, Uganda. (2009). "US AIDS Coordinator Ambassador Eric Goosby visits Uganda" available at www.kampala.usembassy.gov/ambassador_goosby.html

Between 2004 and 2011 South Africa received $3.1 billion US dollars from PEPFAR which provided for a significant scale-up of HIV/AIDS treatment and care programs. In 2009 alone, PEPFAR provided $120 million funds for the bulk purchase of ARV drugs for South Africa. The stated goal of this one-time funding was to help meet the anticipated increased demand to be generated by the HIV Counselling and Testing (HCT) campaign that began in April 2010. This investment facilitated a doubling of South Africa's ARV drug supply (Pisani, 2008).

PEPFAR has recently moved away from direct service provision to funding technical assistance for local NGOs. A study by Victoria Boggiano (2011) highlights the significant reduction in HIV treatment funding since 2008, both as a proportion of total budgets and in absolute dollar amounts. According to PEPFAR Operational Plans through 2010, the percentage of total funding that went toward the supply of ARV drugs, both adult and paediatric had decreased from 35 to 28 percent. Declines varied by country, some saw their grants flat-lined, while others (including Namibia, Mozambique, Kenya, and Tanzania) had lost between 10 and 30 percent of their total treatment budgets by 2010.

### 5.5 Understanding the HIV/AIDS Agenda

The belief that NGOs were organized to meet the needs of grassroots organizations (Caroll, 1992; Fisher, 1993) has been challenged by those who argue that NGO actions are largely shaped by external actors; be it the state (Bratton, 1994; Farrington et al., 1993) or international donors (Michael, 2004; Schuller, 2007). This external influence can be in the form of NGOs tailoring their grant proposals and progress reports to accommodate the specific requirements of funders (Bornstein, 2006; Wallace and Bornstein, 2006).

NGO-required reporting systems, which are today done in a monitoring and evaluation framework, are integral tools in the processes associated with the strategic translation of global HIV/AIDS funding priorities. Through carefully

designed monitoring, evaluation and reporting (MER) systems, PEPFAR has engaged in this strategic translation process. While MER tools are of critical importance for monitoring accountability and progress toward programme outcomes (Fowler, 1995), they should not be used as coercive tactics to further the strategic policy translation process thereby imposing donor-induced demands on grantee or service recipients, i.e., the community being served. On-going documentation through processes like MER and critical analyses of programs should be undertaken by objective, evidence-based organizations where public trust and confidence exist. Without this objectivity, the tasks of evaluating secondary program documents, analysing data, and reviewing stakeholder assessments, can be influenced by preconceived notions of past performance, programs become the victims of past mistakes and repeating them to conform to donor demands.

### 5.6 Monitoring and Evaluation as Strategic Translation

Over the past two decades there has been a growing trend toward the proliferation of quantitatively structured planning, reporting, and accountability systems (Bornstein, 2003). These systems are characterized by carefully designed monitoring, evaluation and reporting aimed at the NGO industry which is increasingly populated with monitoring and evaluation officers, specialists, and technical assistance advisors.

A neo-institutional perspective attributes this isomorphism with private industry to such passive processes as the diffusion of industrial norms and acceptance of power imbalances between donors and NGOs (Cracknell, 2000). Empirical evidence suggests that in many instances these are indeed precipitating factors, there is also some evident that NGOs actively negotiate with and resist donor agendas, although the majority of NGOs are unable to do so for various reasons, the most common one being their overreliance of donor resources (Fowler, 2000).

NGOs in South Africa as elsewhere have a heavy reliance on international donors, private, and government funding to fulfil their various roles in the non-profit sector (Republic of South Africa, 1997). As a result, the fully independent functioning of NGOs is compromised. Using organizational theory as my theoretical framework I demonstrate how international donors have imposed their strategic agendas on local NGOs engaging in a strategic translation process that may, or may not, represent their own organizational mission.

For many international donors, issues of accountability and impact have caused them to impose much greater selectivity in the development projects and type of organizations they will fund. In addition, many have adopted specific planning, implementation, monitoring and evaluation system protocols that link project activities (inputs) and outcomes to their funding decisions (Coleman, 1992). A logical framework that includes specification of objectives that are linked to outcomes is the most prevalent approach used, this framework includes monitoring and evaluation systems that, in theory, allow for better tracking of implementation activities including the early identification of problems (Gasper, 2000; 2002). These monitoring and evaluation systems are designed to concisely communicate key information about the original design, progress, and impact of a project to donors, grantees, and other key stakeholders (Coleman, 1992).

Monitoring is the process of tracking program progress and is intended to inform project management of achievement of project goals and factors that may be impeding such progress. It provides feedback to project team members in a timely manner, and allows for appropriate modifications. Evaluation is the process of measuring program impact and whether it occurs as planned, thus permitting the assessment of adequacy of the overall project design as well as the outputs achieved. While there are many approaches to monitoring and evaluation, many international funders prefer monitoring and evaluation systems that are linked to the logical framework approach (LFA), which is the widely preferred tool for the design and evaluation of development projects and

programs.[40] In a LFA, the overall objectives and implementation strategy for a project are presented in the form of a matrix (Gasper, 2002); all project inputs are linked to specified objectives which are linked to specific outcomes. Project activities are directly linked to indicators of when and whether a particular outcome has been “realized”, “produced” “achieved” and to what extent. These indicators, largely pre-specified by donors at the outset of a project serve as milestones of progress and barometers of the overall effectiveness and impact of a project, consequently they constitute the foundation of the monitoring, evaluation and reporting system to be used.

Ideally monitoring and evaluation systems contribute to sound management functions such as program administration; information sharing and dissemination; risk management; feedback and learning; performance review and assessment; impact assessment; and project team management (Fowler, 1995). However, there are weaknesses intrinsic to the approach, most centrally in the focus on desired outcomes with limited attention to unanticipated effects, more specifically contextual challenges and the belief that the logic of the project design will maintain its coherence when put into practice (Howes, 1992; Gasper, 2002; Wallace, 1997). From my personal observations and experience, the intrinsic weaknesses in the logical framework monitoring and evaluation approaches are compounded, when monitoring and evaluation systems distort development activities and generate fear, anxiety, and deceit within the NGO sector.

In monitoring and evaluation system requirements I have observed that international donors increasingly dictate to grantees the terms of project

[40] The logic framework approach (LFA) has come to play a central role in the planning and management of development interventions over the last twenty years. Its origins lie in a planning approach used by the US military. It was then adopted by USAID for development projects over thirty years ago. It was then adopted by European development organisations in the 1980s and by the end of the 1990s the LFA (or an adapted form of it) had become the standard approach required by many donors for grant applications (Hailey & Sorgenfrei, 2004). Although the logical framework has become universally used, it is not universally favoured. It has been the subject of criticism over the years, concerning both its theoretical basis and the way it is applied in practice (see Gasper, 2000; Bronstein, 2003).

activities, who then must agree to these terms to secure funding. Most international donors require a logical framework approach in NGO applications for funding (Smith and Bornstein, 2002; Bornstein, 2004). They also require a monitoring, evaluation, and reporting system be put into place against which this framework is evaluated, with financial accounts and a tabular progress report is submitted on a quarterly basis. For many local NGOs, these systems make little sense as the monitoring and evaluation activities included are irrelevant to their project. From my personal experience, many donor requirements are a distraction from the work required, confusing and redundant. Hence there are normally ignored and the gaps between on-the-ground activities and what is packaged and produced for funders include exaggerated claims of progress or impact with an effect of secrecy rather than transparency which then produces a negative effect on learning.

**5.7 A Case Study in Strategic Translation: The Sophumelela Clinic**

Based on my six years working in the health-related NGO sector in South Africa, specifically in HIV/AIDS projects, I have observed that international aid to South African NGOs has been accompanied by the conditional requirement of having a system of monitoring, evaluating and reporting in place as a requirement for funding. I argue that these monitoring and evaluation systems have had unanticipated effects on the quality of the work produced and the relationships that develop between donors, governmental agencies, and grantees. Although these monitoring and evaluation systems were put in place to ensure the accountability of NGOs, and to better guide project implementation, my experience is that they often foster fear and deceit, resulting in a systemic distortion and manipulation of information with "cooked" reports that stifle program improvements.

When I started working for Sophumelela Clinic Incorporated (SCI), an East London faith-based NGO in February 2010, I was employed as a Monitoring and Evaluation Officer. Six (6) months later, because of the positive changes the

organisation was experiencing as a result of having a Monitoring and Evaluation Officer together with my growing experience and expertise in AIDS-related NGOs, I was asked to assume the role of providing strategic information to the management team.

At a later date, I was asked to be the Project Coordinator of all HIV/AIDS programmes while still performing my Monitoring and Evaluation Officer functions. As a Monitoring and Evaluation Officer, one of my key roles was to understand donor monitoring, evaluation and reporting and compliance requirements, particularly those associated with USAID, PEPFAR and the Global Fund. I gained this knowledge very quickly through periodic trainings from these donor agencies on what was expected of me as Monitoring and Evaluation Officer and my role within the organisation. One issue I quickly identified was that SCI lacked a 5-year strategic plan. I advised them to consider having such plan in place. On discussing this need for a strategic plan with the donors, they immediately offered to fund a 5-day strategic planning workshop to enable SCI to develop its 5-year strategic plan. This strategic planning workshop was to be facilitated by the donors. A team comprised of an HIV/AIDS Program Specialist, Monitoring and Evaluation Specialist, Finance and Administrator Specialist, Human Resources Specialist, and an Organisational Development Specialist were flown to East London from Uganda and the U.S. I was asked to be the SCI lead person in my capacity as Monitoring and Evaluation Officer.

After the 5-day workshop, the vision, mission, aims, and objectives of SCI were modified to conform to the requirements of the international donor agency. From my perspective, this was an example of how strategic translation occurred in SCI as it was subtly persuaded to modify its vision and mission statements to conform to the donor's requirements for funding. As a result, SCI was guaranteed renewal of its grant for another two years in some of its key programmes.

I was approached by the donors to inquire whether SCI would expand its Home Based Care (HBC) programme as well as introduce an Orphan and Vulnerable Children (OVC) programme from the pre-school through preparatory school run by SCI. The school was comprised of HIV-positive orphaned children and also children born from HIV-positive parents. In the expansion of these two programmes I was once again asked by SCI, with the recommendation of the donor, to become Project Coordinator of the HBC and OVC programmes in addition to my previous responsibilities. As HBC and OVC Project Coordinator, one of my roles was to help look for funding of these two programmes from other potential donors, I then became involved in writing and developing proposals for funding. Within two months, SCI was received funding for both programmes from the Global Fund through an organisation called the Networking AIDS Community of South Africa (NACOSA), who are the Global Fund grant holder in South Africa.

Again, as Monitoring and Evaluation Officer, and now Project Coordinator, I was now in a position to master Global Fund/NACOSA compliance, monitoring, evaluation and reporting protocols. I therefore attended training courses and workshops on Global Fund/NACOSA donor requirements and compliance issues. Just like USAID/PEPFAR donors, we were expected to meet specific targets to receive funding. The OVC programme was fully funded by Global Fund and HBC was partly funded by both the Global Fund, USAID/PEPFAR, therefore SCI needed to comply with the requirements and conditions of each funder. This case example demonstrates the fundamental power imbalance between international aid agencies and their grantees.

### 5.8 The Lusikisiki Case Study

Many of the same strategic translation activities I observed during my tenure at SCI were also observed in the Lusikisiki community which is the topic of this dissertation. The Treatment Action Campaign (TAC) operating as a local NGO partner in the Lusikisiki project used what they called "*Treatment Literacy Weekly Work Journal*" as a social media vehicle for reporting the activities of the project.

This reporting mechanism was largely populated with data provided by MSF, the international NGO receiving PEPFAR funds that subsequently funded the activities of the TAC. Monthly, quarterly, semi-annual and annual reports were generated from these *Treatment Literacy Weekly Journals*.

The journal had two sections: a narrative section which sought to document process and/or qualitative data, and “Stats of the Week” [weekly statistics] which documented statistical/quantitative data. Although the design has since been questioned, the TAC reported four key indicators: 1) *Number of new ARV clients for the week*; 2) *Number of people who visited VCT*; 3) *Number of ARV defaulters*: and 4) *Number of home visits*. An indicator not reported was number of accredited ARV sites.

The reporting template included what MSF chose to have the TAC report. My attempts to understand the purpose of the indicators selected for the *Treatment Literacy Weekly Work Journal* from TAC volunteers were frustrated because they did not know who was responsible for designing the data collection template, all they knew was that it was provided to them by the MSF Lusikisiki Project Coordinator. Monthly, quarterly, semi-annually and annual reports were more comprehensive as they included indicators such as meetings held with the Provincial Department of Health, campaigns or demonstrations held, community mobilisation sessions held, and so on. One of the characteristics of MSF as a humanitarian international NGO was its focus on mobilising local people to demonstrate and hold community campaigns as a way of expressing their needs to the relevant authorities.

Exit strategy meetings were also designed by the MSF in an attempt to ensure that the TAC’s role would be sustainable when MSF exited the community. The meetings started in January 2006, nine months before the departure of MSF from Lusikisiki. I attended a couple of these exit strategy meetings as an observer. The meetings were chaired by the Assistant MSF Project Coordinator and were

attended by the TAC Eastern Cape Provincial Coordinator, the TAC Lusikisiki Administrator, and the MSF Resource Centre Coordinator. I found it curious that no one from either the local, district, or provincial Departments of Health were invited or represented, this despite the fact that the Eastern Cape Department of Health had agreed to take over the HIV/AIDS programme once MSF exited the community. The leaving of MSF threatened the closure of the TAC office in Lusikisiki, so it was for this reason that the exit strategy meetings were held. It is possible that not inviting the Department of Health to these meetings was to allow for more freely discussed strategies about how to ensure the TAC's existence with the absence of MSF support.

The meetings normally discussed the current TAC/MSF partnership, their joint action planning document, and the current TAC budget. During these exit strategy meetings the idea of forming a new NGO was hatched, one which would play a similar role that MSF played with the TAC; the role of Department of Health was tabled and imposed by MSF. The primary difference between the newly conceived NGO was that it would not be headed by a medical person or have a medical team but rather be headed by an adherence counsellor and it would be comprised of all former MSF employees.

The new NGO became known as the HIV/AIDS Adherence Counsellors Organisation (HAACO). By April 2006, HAACO was established with a board of directors. From then on employees of the HAACO joined the exit strategy meetings. All re-forming ideas came from the MSF who continued to take the lead in all discussions. Subsequently, a number of potential donors were approached by MSF to fund HAACO; these funders included the Elton John AIDS Foundation, the Nelson Mandela Foundation (NMF), and the Dutch Embassy. In the meantime, MSF cut its funding to TAC and focused its financial support on HAACO. TAC's Lusikisiki funding was cut to R200 000 per year with the MSF requirement that this money be spent for activities in the Lusikisiki community (or at least Quakeni District). The money was expected to be

increased by MSF only if the TAC demonstrated its capacity to develop a Treatment Literacy Community Training Programme in Lusikisiki. MSF agreed to fund the TAC R50 000 every 3 months on the condition that MSF received documentation about how the TAC spent these funds. Since the TAC did not have a Monitoring and Evaluation Officer, the TAC Eastern Cape Provincial Coordinator was tasked with the role, presenting an activity report to MSF every 3 months. Other reporting included financial reports put in place by MSF. The TAC had little say about the content or format of these reports as they were entirely dependent on the funds provided by MSF to keep the Lusikisiki branch office open.

It became clear in my working in the AIDS NGO field that local NGOs are largely passive recipients of international donors funding because local NGOs are almost entirely dependent on this source of funding. While NGOs are widely regarded as agents of change and catalysts for social and economic development, the relationship between NGOs and donors will likely remain contentious and controversial (Nauta, 2001).

**5.9 Strategic Translation Engaged**

Strategic translation is a concept coined by Wiebe Nauta (1999) in his discussion about the intermediary role played by NGOs with regard to international donor agencies in the land use sector. Nauta explained how the intermediary position of an international land use NGO, the Monti Rural Association (MRA), provided staff with the advantage of imposing its own agenda as representing community need, and then proceeded to cause the community to internalise this agenda despite contrary evidence. Nauta demonstrated how a powerful international NGO, funded by international donors, strategically translated its own agenda and priorities on a community in the manner that suited their political needs.

According to Nauta, community needs are co-opted and in some cases completely ignored, while new community needs are created. Although

workshops and community meetings that include needs assessments and situational analyses are conducted, the reports that are generated rarely reflect communities articulated needs. Nyamwaya noted some time ago that in the health sector;

> …while in theory communities are supposed to play a leading role in the health-development process, the process is still largely controlled by government and NGO development 'experts' who do not allow communities to play a major role (Nyamwaya, 1977: 184).

Such processes of control and manipulation result in what Nauta coined as strategic translation. From my personal experience in AIDS-related NGOs, evaluation and research, strategic planning workshops, and the subsequent reports that are produced become tools to inform the strategic translation process. With the introduction of indicator-based monitoring, evaluation and reporting systems, PEPFAR has perfected the process of strategic translation. In the context of the Lusikisiki Project, I learned first-hand that the HIV/AIDS activist community, and not the community at large, defined the parameters of the Lusikisiki Project.

### 5.10 PEPFAR's Use of Indicators in the Strategic Translation Process

Indicators are developed through a process linked to the logical framework approach (LFA). They are developed as part of a program matrix in which a project's objectives and expected results are clearly identified and assigned a list of indicators to be used for measuring, i.e., quantifying progress towards achieving specified objectives and outcomes (Commission of the European Communities, 1993). The logical framework is the primary organizing tool for monitoring activities in programs administered by NGOs. As demonstrated by previous examples, the logical framework is primarily geared towards collecting quantifiable data which is oriented to measuring results. These indicators are amenable to being displayed on a spreadsheet. They are not amenable to measuring qualitative processes, including political, social and other dynamics

that can equally affect program outcomes and impacts. In short, it is the quantifiable indicators that are primarily used as tools for strategic translation and are designed by outside development experts based on assumptions which do not consider the environmental context in which programs operate.

### 5.11 The Impact of Chasing Numbers

The discrepancies between what NGOs and donors say and what they actually do can be quite damaging to the communities in which they operate. The desire to 'save face' in order to maintain a good reputation with either governmental agencies or other powerful stakeholders, appears to be a main motivator of misrepresentation. These discrepancies lend support to the view that unrealistic donor demands are an obstacle to openness and transparency. Challenges that hinder meeting unrealistic targets can actually divert a donor's policy agenda. As a person directly involved in periodic reporting to donors, I understand the negative impact of reporting unrealistic targets and the frequency of "cooking the data" to achieve unrealistic ends.

The NGO sector has recently been described as undergoing a 'crisis of accountability and transparency' which is damaging to its credibility (McGann and Johnstone, 2006). Despite rising pressure for more openness and transparency, many NGOs are reluctant to share information honestly, and refuse to honestly participate in accountability processes for fear of losing their funding (Elkington, 2003). This is highly problematic as transparency is a key requirement for good governance based on successful feedback systems. In sum, NGO relationships with their donors are fraught with information asymmetries, which make it difficult for donors, governmental agencies and communities to hold any of these stakeholders truly accountable.

In the next chapter, I discuss the interplay between the tripartite alliance formed by the TAC, MSF and the Eastern Provincial Department of Health in the governance and policy-setting of the Lusikisiki HIV/AIDS programme.

## Chapter 6: Strategic Alliance: The Tale of an Embedded Partnership

The relationship between government and civil society organisations (CSOs) in many developing countries is quite delicate. Some governments question the legitimacy and true representative nature of CSOs and instead view them as unrepresentative opposition (UNDP, 2012). Further, strong external donor support for these organizations is seen as supporting this government critique and posing possible interference in the internal workings of the government in question (UNDP, 2012). Bilateral donors have supported CSOs for a long time for reasons either of expediency (a convenient way of implementing activities) or as a governance tool (wanting to strengthen civil society in democratic development).

The aim of this chapter is to critically examine the tripartite alliance between a local CSO, the Treatment Action Campaign (TAC), its international NGO partner, Mèdecins Sans Frontiéres (MSF), and the Eastern Cape Department of Health (ECDOH) in the battle against HIV/AIDS in the Eastern Cape Province community of Lusikisiki.

I will discuss how these partners interacted with each other, the nature of the relationships that developed, the evolution of the TAC as it re-invented itself to remain relevant to its international partner (MSF), and the community's perception of the alliance. Central and key to this chapter is the role played by the TAC in representing, or not, the needs of the Lusikisiki community.

### 6.1 Objectives of the Lusikisiki Partnership and Collaboration

The programmatic objectives that underpinned the initiation of the Lusikisiki HIV/AIDS programme were multi-faced. First and foremost, the politics surrounding HIV/AIDS treatment in South Africa, including the roll-out of antiretrovirals (ARV drugs) called for an aggressive and immediate response. The opportunity afforded by an international NGO (MSF) willing to partner with a

local CSO (the TAC) to successfully provide access to anti-retrovirus (ARV) medications to poor communities had already been demonstrated in the Khayelitsha Township outside Cape Town (Beresford, 2004; Robin, 2004b). Critics questioned whether such an alliance could be replicated in a highly rural setting. An equally important question was whether the efficacy of ARV treatment was understood by the Lusikisiki community. MSF had a strongly held belief that if you “provide decent treatment, people will come and get it, no matter their circumstances” (Steinburg, 2008: 4). Steinburg provides a somewhat ambiguous description of how people in Lusikisiki understood HIV/AIDS which he argued was embedded in traditional African culture. Unfortunately, he failed to do justice to the fact that there were at least two competing ways of responding to the disease in terms of treatment, on-going care and support, and education and prevention. The priority to dispense ARV drugs, the primary objective of the tripartite alliance, did not necessarily reflect the community’s top priority as it grappled with the full implications of the HIV/AIDS epidemic in its local context.

The Department of Health’s (DOH) reasons for joining the partnership were articulated by then member of the Executive Council (MEC) for Health in the Eastern Cape provincial government Nomsa Jujula in the MSF close-out report;

> “The Department of Health’s mandate is the provision of efficient and cost-effective health care services for the people of the Eastern Cape. This can be achieved through partnership with stakeholders, such as NGOs. MSF and Nelson Mandela Foundation provided the Department with unique expertise and resources…” (2006: 2).

**6.2 The National Department of Health**

The National Department of Health (NDOH) is the governmental body that reports to the South African Ministry of Health. The mission of the South African DOH is to improve “access to health care for all and reducing inequity, and to focus on working in partnership with other stakeholders to improve the quality of care of all levels of the health system, especially preventive and promotive

health, and to improve the overall efficiency of the health care delivery system" (DOH, 2007: 19).

The South African health care delivery system is characterised by four levels of government: national, provincial, district, and local. The national DOH oversees the national HIV/AIDS plan, commonly known as the National Strategic Plan (NSP). The broad HIV/AIDS policy framework is designed at the national level while the provinces are assigned the responsibility for its implementation. The national DOH sets norms and standards for the provision of health services, then collects and distributes the available funds to the provinces who are given responsibility to allocate these funds to local service providers (Jones, 2004c; Mogale, 2003; Schneider and Gilson, 1999).

In Lusikisiki, the local DOH is an arm of the Oliver Reginald Tambo Provincial Health District which covers the local service area (LSA). The district level of government was introduced in 2006 so that local governments would no longer report directly to the Province, but rather through a district that would serve as a conduit to the provincial level.

### 6.3 The Treatment Action Campaign: A local advocacy partner

The Treatment Action Campaign (TAC) is commonly known as a 'social movement,' a South African CSO that advocates for access to treatment for people living with HIV/AIDS (PLWHA). Its primary role is to work towards the elimination of new infections and to end discrimination against PLWHAA. From its formation in 1998, the TAC has advocated for the government to negotiate the purchase of lesser expensive generic drugs. Because of its successful activities at all levels of government in representing the rights of PLWHA, the TAC had become a national and international known CSO. It has grown from 5 members in 1998 to thousands of members, volunteers and supporters. It now has provincial offices in KwaZulu-Natal, Gauteng, the Eastern and Western Cape with branches in Limpopo and Mpumalanga.

From its founding, the TAC has employed networking and partnerships as vital tools to achieve its objectives. One such partnership is its alliance with the Congress of South African Trade Unions (COSATU), a partner with the ANC, the South African Communist Party (SACP), and the international NGO, MSF. Positioning itself with COSATU was critical to its strategic political alliances.

Networking is an important activity for any organization that strives for success and sustainability. Through networking, organisations garner various kinds of support from other organisations thus expanding opportunities for growth and development. While the TAC operating in Lusikisiki had a strong alliance with its NGO partner, the MSF, the same cannot be said about its alliances with other influential organizations in the Eastern Cape.

The TAC's relationship with the Eastern Cape Department of Health was intermittent and generally difficult to sustain. The strength of the Lusikisiki TAC's relationship with other NGOs in the area was questionable as contact generally was limited to monthly or less frequently timely meetings. For example, the TAC offices in East London which house the Eastern Cape Province's head office, have failed to develop working relationships with key organisations such as the Eastern Cape AIDS Council (ECAC) and the Eastern Cape NGO Coalition (ECNGOC).

The national TAC has strong ties with big international NGOs such as UK DFID (United Kingdom Department for International Development), Oxfam, MSF, the European Coalition of Positive People, FOTAC, Health Gap, and Ralph Nader's Consumer Technology Project in the United States. It also networks with national CSOs, social movements, and NGOs, including COSATU, the largest labour union federation in South Africa and the AIDS Law Project, which supports much of its legal work. However at local level, in this case the Eastern Cape, it had superficial relationships with NGOs including the Council of Churches, several

religious groups and faith-based organisations, and other governmental agencies such as the South African Police Services, the Department of Social Development, and the Department of Education. Despite its emphasis on grassroots mobilisation and networking with community organizations, its ties with local NGOs and CSOs was weak. Some volunteers interviewed for this study on condition of anonymity blamed this weakness on its militant, confrontational, and aggressive approach.

According to reports, including my interviews, the TAC in the Eastern Cape is currently 'working' with 22 partner organizations that have voiced confidence in the TAC programmes despite the weak and superficial relationships with these organisations. All the CSOs and NGOs that were informally interviewed acknowledged the TAC's significant and exemplary role in the fight against HIV/AIDS, particularly in poorer rural communities. A number of the TAC volunteers interviewed on the condition of anonymity reported being attracted to the TAC because of the unique advocacy role it played in their community.

The TAC has positioned itself as a diverse and effective HIV/AIDS-focused CSO that has responded to the epidemic in South Africa, one which crosses all socio-economic and political boundaries. Hence, the TAC has demonstrated that HIV/AIDS is not simply a health issue, but rather a political, development, cultural, and gender-based issue as well (UNAIDS, UNFPA and UNIFEM, 2004; Govere, 2005).

The self-described mission of the TAC relative to the HIV/AIDS epidemic is that it provides the most powerless citizens in South Africa the ability to become active and effective advocates on their own behalf and that of the communities in which they live (Ballard, 2006).

As an HIV/AIDS activist CSO, the TAC is unique in that it has combined the direct action tactics of North American AIDS groups, such as AIDS ACT UP with

the culture-specific community mobilisation actions of South African trade unions and anti-apartheid organizations. While the TAC has framed its various campaigns on a rights-based discourse, it also draws heavily on the potent tradition of South African civic society which struggles for political equality and social justice as exemplified by the anti-apartheid movement.

The TAC concentrates its programme activities on the working-class and materially and intellectually marginalized citizens of South Africa; hence it is not coincidental that the Congress of South African Trade Union (COSATU), having lost thousands of workers to the AIDS epidemic, readily joined TAC campaigns (Robins, 2004). One key to TAC's successful campaigns is its emphasis on grassroots mobilization which is accomplished through programmes such as HIV/AIDS awareness, education, and treatment literacy campaigns held in communities, factories, workplaces, funerals, in schools, and through door-to-door visits in townships and local clinics.

TAC's membership has grown dramatically over the past several years with a rank-and-file membership that is dominated by young Black African women. In addition, it has attracted health professionals, university graduates, individuals who have completed secondary programmes, and people of varying professions, most of whom are HIV-positive or have HIV/AIDS-infected family members. The majority of TAC volunteers are poor, unemployed black African women, many of whom are single HIV-positive mothers. In Lusikisiki, more than 90 percent of TAC staff and volunteers are comprised of women.

### 6.4 Community Perceptions about TAC

TAC staff and volunteers from Lusikisiki define the organization by the services offered to the community,

> *TAC educates community members about HIV/AIDS-related diseases such as STDs and TB…it also provides awareness campaigns and assists abused people of their rights. TAC also helps the poor get food parcels from the department of Social Welfare.*

> *TAC supports HIV/AIDS programs, helps people access HIV treatment, promotes the use of condoms, and educates people about Nevirapine for mother-to-child transmission.*
>
> *TAC is an organisation fighting for the rights of the community with a focus of HIV/AIDS…it equips communities on ways to deal with HIV and live positively with the disease. TAC gives people advice about living with AIDS and about their rights and the services to which they should have access from clinics and the government.*
>
> *TAC is an organisation that advocates for human rights, especially for people living with HIV/AIDS.*

The TAC website states that it is a civil society organization intending to, "promote treatment awareness and treatment literacy among all people; campaign for AZT and Nevirapine for pregnant women to prevent mother-to-child transmissions; campaign against profiteering by drug companies and other bodies; build a mass TAC membership; build networks and alliances with unions, employers, religious bodies, women and youth organizations, lesbian and gay organizations and other interested sections of the community; maintain TAC visibility through posters, pamphlets, meetings, street activism and letter writing; and target pharmaceutical companies to lower the costs of all HIV/AIDS medications and maintain pressure on the government to fulfil its HIV/AIDS obligation" (www.tac.org.za, Accessed 17 August 2006).

**6.5 TAC as a Service Provider**

One of the core enduring services offered by TAC is HIV/AIDS education. Through its Treatment Literacy Programme (TLP), the TAC has been able to be self- sustaining. The TLP has taught HIV-infected people that being HIV-positive is no longer a death sentence. Building on lessons learnt from a small scale pilot project it started together with MSF in Khayelitsha called Project Ulwazi, the TAC expanded the TLP curriculum and built the knowledge base for HIV-positive advocates and their communities (Boulle and Avafia, 2005). Topics covered in the TLP include prevention of HIV, general health and HIV, epidemiology of HIV,

the science of HIV and treatment, risks of opportunistic infections, mother-to-child transmission, antiretroviral therapy, post-exposure prophylaxis, safe sex, nutrition, and the social impact of HIV on communities.

The TAC has used a mix of civil disobedience, protests, marches, court action, political rhetoric, and the media to successfully engage governmental agencies in its agenda. By joining forces with trade unions (COSATU), the South African Communist Party (SACP) and other CSOs in its advocacy campaign, “The TAC and trade unions, together with other civil society formed part of lobby group to search for a woman-friendly presidential candidate to replace Mbeki” (Gumede, 2007).

**6.6 Mèdecins Sans Frontiéres: An International Ally**

Headquartered in Geneva (the seat of WHO) and Brussels (the seat of EU), Mèdecins Sans Frontiéres (MSF), commonly known as Doctors without Borders, is an international humanitarian organisation founded in 1971 by a group of French physicians. Its mission is to help victims of armed conflict, epidemics, natural and man-made disasters, and to assist those who lack access to health care due to geographical remoteness, ethnic or political marginalisation. The beginning of MSF’s involvement in South Africa’s HIV/AIDS epidemic was in May 2001 in association with three hospitals in Khayelitsha Township, Cape Town when they started providing antiretroviral therapy (ART) to HIV positive people. The treatment took place in HIV/AIDS dedicated clinics run by MSF. Based in the Western Cape, MSF launched the first prevention of mother-to-child transmission (PMTCT) programme in the country in Khayelitsha.

In 2003, MSF expanded its services to the Eastern Cape Province as a result of the strong ‘encouragement’ of Western Cape TAC members whose roots were in the Eastern Cape Province, Lusikisiki in particular. As noted by a MSF doctor;

> “We would not be here if it was not for TAC’s mobilizing and campaigning demanding a pilot site. Also we have 91-95% adherence on our ARV programme thanks to TAC” (Interview with Herman Reuter, October 2006).

In consultation with the Eastern Cape HIV/AIDS Directorate in Bhisho, and with the approval of the then Member of the Executive Council (MEC) of Health, Dr. B. Goqwana and Premier Stofile, MSF started an HIV/AIDS Programme in Lusikisiki in 2003 (Médecins Sans Frontières, 2003). In addition to establishing an HIV/AIDS Programme in Lusikisiki, MSF provided funding support to establish a TAC branch office in Lusikisiki. From its launch in 2003, MSF worked in partnership with the TAC to advocate for increased access to HIV/AIDS treatment. Together, the two organizations supported community education about treatment options, promoted the use of fixed-dose combinations of ARV drugs, and monitored the impact of HIV/AIDS treatment (Médecins Sans Frontières, 2004). The partnership between MSF and the TAC has been critical to TAC’s influence and success in the fight against HIV/AIDS in South Africa. Besides providing financial and management support, MSF also provided direct treatment services to TAC members (Boulle and Avafia, 2005).

MSF greatly expanded access to HIV testing and ensured that HIV-infected individuals had access to ARV drugs during its tenure in Lusikisiki (Steinberg, 2009). Despite its withdrawal from Lusikisiki in October 2006, MSF has remained committed to continued engagement in HIV/AIDS and Tuberculosis (TB) activities in South Africa.

To graphically sum-up the influence of MSF in Lusikisiki, a TAC activist describes its impact in his life;

> “*I come from Cala but I stay in rural area called Lusikisiki, in the Eastern Cape. I was diagnosed HIV-positive in 2002. In the hospital, I was advised that I should be sterilised, because I was told that all my children would be HIV-positive. I didn’t know anything then. I was also supposed to have an operation for piles, but I couldn’t do both because I wasn’t well enough. I was sterilised and stayed in hospital for a few days, then went home.*

*The sores on my private parts I'd had come back and this time they were bad. I told my aunt. She took me to the hospital and afterwards took me to her house. She took care of me till I got better. I want to thank the Ntsaba, Ndungane, and Mthyali families, because they all took care of me. My mother and father have also been very supportive.*

*At the end of 2002 I went to the Médecins Sans Frontières (MSF) clinic in Khayelitsha, Cape Town, which my aunt's friend introduced to me. I told them I was living in Lusikisiki. The doctor was concerned that I would go back to an area where ARV drugs were not available, but I went anyway. In 2003, I joined the Treatment Action Campaign (TAC) in Lusikisiki and luckily enough, MSF was there, working very closely with the TAC.*

*In my work for the TAC I was educating people about VCT, CD4, PEP, TB, rape and ARV drugs. One day, I decided to do a CD4 count; the result was 151. I was scared to start ARV drugs. But on December 10, 2003, I took my first pill, which was given to me by Nelson Mandela himself. I was so happy to see him taking a political lead on ARV drugs and believing that ARV drugs can save people's lives.*

*In my room, I kept a poster of Mandela as a reminder to take my ARV drugs. I took him as my ARV supporter. The last time I did my CD4 count, it was 860 and my viral load was undetectable. I am healthy and I am taking AZT, 3TC and Nevirapine. I have gained weight since 2003.*

*I thank MSF in Lusikisiki for saving people's lives in a rural area. We will always remember your good work. We need more people like Madiba, TAC and MSF, to fight the struggle against HIV and AIDS in South Africa. Pambili nge-ARV drugs! (Forward with ARV drugs!)*

### 6.7 Partnering with the Department of Health in Fighting AIDS

With moral and financial support from Nelson Mandela Foundation (NMF), and in partnership with the ECDOH, MSF expanded its HIV/AIDS programme to Lusikisiki, one of the poorest and most rural areas in the Eastern Cape. The *Siyaphila La* ART (antiretroviral) programme was launched by former president Nelson Mandela who administered the first pills to an HIV positive woman. *Siyaphila La* means "We are living here" in Xhosa. *Siyaphila La* is recognised by Eastern Cape provincial government as an official programme to initiate ART in the province.

An October 2006 joint report issued by the Nelson Mandela Foundation (NMF) and Mèdecins Sans Frontiéres (MSF) included a foreword by Nomalanga Makwedini, the then Chief Director of Primary Health Care in the Eastern Cape Department of Health. The report noted the confidence that the DOH had in MSF to train nurses to manage the related medical problems of PLWHAA and the development of a cadre of community caregivers engaged in health promotion and the provision of VCT services (Nelson Mandela Foundation and Médecins Sans Frontières, 2006).

In my interviews and informal conversations with community members in Lusikisiki, the TAC and MSF were conceived as constituting one organization. In reality, the TAC branch was established in Lusikisiki by MSF shortly after it arrived from the Western Cape Province as a result of the pressure MSF received from the TAC members in the Western Cape who were originally from Lusikisiki, they knew the toll of lives taken by HIV/AIDS in this poor and remote rural area. Thus MSF and the TAC in Lusikisiki had a previous history of working together and since they both arrived in Lusikisiki around the same time, the boundaries between the two was at times blurred. MSF viewed the TAC as a valuable CSO which could launch campaigns against the government's then denialist policy on AIDS;

> "We [MSF] needed someone to put pressure on the government ..., and that was TAC. We work hand-in-hand with TAC, we fed them with information and they act on it …" (Interview with Herman Reuter, 2006).

Others also noted the tense relationship between the TAC and the national DOH, a relationship where cooperation and conflict coexisted;

> "One of the worst things about TAC is its relationship with the national government because it affects us here. There is such a need at clinics, yet if we say we are from TAC we are not allowed in. Sometimes I lie and say I am from a community support group just to get into the clinic or hospital.
>
> "TAC is too focused on the Health Minister. It [sic] distracts us from the real work. I think it is time to ignore her." (Anonymous TAC Volunteers, quoted in Boulle and Avafia, 2005).

> "TAC is at times aggressive where it is not necessary. For example, there were no gains to Zackie Achmat's public fights with the minister at the Health Systems Trust conference. TAC's aggressiveness just alienated people." (Anonymous government official, quoted in Boulle and Avafia, 2005).

This tension between the seeming cooperation and then conflict resulted in an antagonism that permeated governmental agencies at all levels−national, provincial, district and local. One government official that I spoke with did not mince his words as he described the TAC as "a snake and an enemy that should be either watched very carefully or destroyed." Another government official had this to say;

> "We are tired of TAC's noises…. And its relationship with organizations such as MSF here in Lusikisiki is suspect. Dr. Herman [Reuter] is a good doctor who is helping our people, but I don't trust him because of his friendship with TAC" (Anonymous).

According to Dr. Reuter, the lack of clear policy made the relationship between the TAC and DOH confrontational and difficult. He believed that there was still some hope that this would change and the two organizations could work together cooperatively. The DOH would remain a major stakeholder in all subsequent HIV/AIDS initiatives.

### 6.8 The TAC and MSF Alliance

> "We would not be here if it was not for TAC's mobilizing and campaigning demanding a pilot site. Also we have 91-95% adherence on our ARV programme thanks to TAC" (Herman Reuter, 2007).

For the TAC, the partnership enabled it access to the Eastern Cape Department of Health, who had refused to meet with them; continually using administrative processes to delay scheduling meetings. The partnership also enabled the TAC to demonstrate to its members and their families the tangible benefits of treatment and thus encouraged a remarkably high level of testing and disclosure.

A combination of the above resulted in spin-off benefits in the de-stigmatisation of HIV/AIDS, increased empowerment of women, the emergence of a gay and lesbian community living openly, and the placement of Lusikisiki on the health service map in South Africa (TAC Evaluation, June 2005).

The alliance of the TAC and MSF in Lusikisiki resulted in a valuable resource for the community of Lusikisiki and surrounding areas. This partnership in Lusikisiki is believed to have created a viable model for other South African provinces. What the partnership between these two organizations achieved included MSF successfully establishing an ARV treatment site in a significantly under-resourced, rural community. In addition, the decentralized treatment model that was based in a community clinic as opposed to a hospital that implemented the widespread use of CD4 cell count machines, saw improvements in the payment of disability grants, and donated the Anglo-Gold Clinic to the DOH as the new village clinic site was a model that could be imported to other rural, under-resourced communities (Boulle and Avafia, 2005).

The distinction between MSF and the TAC was made clear in meetings between the Eastern Cape DOH, TAC, MSF, and other local NGOs in Lusikisiki.

> "In meetings we (MSF), take a neutral position between TAC and DOH, who rarely see eye-to-eye. We obviously have [had] to pretend, knowing very well that we are on the TAC's side…We saw the TAC as front that we therefore used to make things happens in community and in the government." (Interview with Jouquet August 2006) [41].

The TAC's relationship with the DOH was confrontational. Furthermore, in public spaces the TAC was vocal, aggressive and militant in its approach with the DOH.

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[41] Guillaume Jouquet was a staff member with Medecins Sans Frontieres staff, working as an assistant Project Coordinator to Dr. Hermann Reuter.

### 6.9 Community Perceptions of the Tripartite Alliance (MSF, TAC, and DOH)

While the provincial DOH viewed the TAC and MSF as separate organizations, the community often saw them as one because of their unified approach to working in the community. Community members, TAC staff and volunteers, MSF staff, and other key informants from Lusikisiki had this to say about the local TAC-MSF-DOH alliance;

> *"Doctors from the Department of Health don't have passion for their work, and they claim that the focus is not on HIV/ AIDS…"*

> *"The working relation between TAC and the DOH is beginning to change…in the beginning they didn't recognize us, now it's a better, they know us, they didn't want us to go to clinics to educate people, now they call TAC to work with them. TAC does workshops with the DOH."*

> *"The relationship between the DOH and TAC is not really perfect…TAC is seen as a threat. MSF-TAC has a good relationship…the DOH doctors don't go to clinics regularly as was happening with Dr. Hermann, the MSF doctor. Dr. Hermann used to do more work than the work that doctors from the DOH are doing. Go to the community and ask them… they are always complaining now that MSF is gone."*

> *"DOH needs guidance on running of the treatment programme, but they won't come to TAC because they don't like us."*

> *"It's painful that MSF is gone and this is a big challenge for the DOH."*

> *"TAC-DOH relationship is fine, but sometimes they quarrel because of the ups and downs."*

> *"Doctors from the DOH don't visit sites for ARV drugs which leads to a long waiting list. …… We are scared because MSF left. Things are no longer the same."*

> *"TAC-DOH relationship is sometimes good and other times bad. For example, DOH gets angry with TAC when demanding something."*

> *"MSF-TAC relationship is very good. We work with MSF when doing VCT, visits ARV sites, education and we use MSF counsellors"*

> *"There is a challenge now that MSF left, doctors from the department don't visit sites, we have shortage of OI treatment, e.g. Fluconazole."*

*"People are dying now because MSF is gone, people can't go to hospital*."

*"MSF worked closely with TAC. MSF gave ARV drugs and TAC gave information on ARV drugs; educated people in community; educated them on HIV/AIDS and VCT*."

*"The relation of TAC-DOH is up and down… but the department think TAC fight them…it's not health at all*."

*"Our role as MSF is to capacitate the DOH run ARV sites and all the aspects of HIV/AIDS."*

*"Lack of policy makes the TAC-MSF-DOH relationship confrontational sometimes, but now it's changing and becoming cooperative."*

*"MSF is task-goal oriented. It also helps shape TAC's leadership and it resources them both financially and otherwise."*

*"We (TAC) get some information from MSF…It is very difficult to get information from the DOH, even HIV/AIDS stats."*

*"TAC helps make things happen both in community and in the government. Community members think TAC and MSF are one and the same thing."*

*"Sometimes we push and encourage TAC to fight the DOH."*

*"TAC does aggressive lobbying, community mobilization, toyi-toyi and speeds up the process from the bottom*."

### 6.10 MSF's Exit Strategy from Lusikisiki

In its efforts to make the Lusikisiki HIV/AIDS programme sustainable and continue after its departure from Lusikisiki, MSF forged an 'Exit Strategy Plan' leading to the formation of HAACO, a new NGO comprising ART adherence counsellors.

Adherence counsellors had been the backbone of the HIV/AIDS programme during the years of MSF's presence in Lusikisiki. Their work was supported by a grant from the Royal Netherlands Embassy to MSF. In mid-2005, MSF started discussions with all its collaborators on an exit strategy that was scheduled to be finalised by the end of 2006. During this period, the key elements of the

programme were clearly articulated and the challenges accompanying a transition of responsibility from MSF to a governmental agency were recognised. The aim was to ensure continuity of service delivery once MSF left Lusikisiki, including treatment delivered by nurses and needed patient support from adherence counsellors, but many deemed it was too little too late. By the time MSF departed Lusikisiki most programmatic elements had been handed over to the Eastern Cape Department of Health. Some essential services, mostly those which required a shift in national and provincial level policy, were still in the process of being legitimized by governmental regulators, adherence counselling was one such service.

The crucial role of adherence counsellors in the roll out of ART had been acknowledged and legitimised by the National Operational Plan for Comprehensive HIV/AIDS Care, Management and Training (www.hst.org.za, accessed November 2003). Some provincial DOHs, such as the Western Cape, allocated financial resources to NGOs in their districts to cover these services; while other provinces, particularly those most rural, had not yet created financing mechanisms to support the function, the Eastern Cape being one of them. With the formation of the HIV/AIDS Adherence Counsellors (HAACO) NGO, it was hoped that HAACO could circumvent The Eastern Cape DOH's reticence to pay for adherence counsellors.

### 6.11 Ensuring Sustainability

HAACO was formed by MSF in order to ensure the continued role of adherence counsellors as they formed the backbone of the programme. HAACO was formed with 19 adherence counsellors, one financial manager and one project manager, all of whom were previously employed by MSF in these same capacities. Similar to TAC volunteers and members, the majority of the adherence counsellors were PLWHAA who had been initially recruited from the pool of volunteers in each of the MSF clinics in Lusikisiki.

HAACO had the dual role of service provider and advocate. The core program objectives and duties included:

- Ensuring that individuals entering treatment adequately understood ARV therapy (treatment readiness);
- Providing on-going drug adherence support for people already on ARV drugs; and,
- Gaining recognition and support of adherence counselling services by the Eastern Cape Department of Health.

Adherence to the ARV therapeutic regimen was essential to achieving sustained viral suppression for individuals with advanced stages of HIV infection (World Health Organisation, 2002). Adherence support is recognised as one of the most important components of an ARV programme, together with simplified treatment protocols, since it helps people understand the reasons behind having to take medication and to confront the barriers they face in complying with their treatment schedules. In the Khayelitsha project it was found that a well-defined patient-centred approach to adherence support was critical to achieving a 72 percent retention rate, with 83 percent of patients still on a first line regimen after 5 years of treatment (Zackie Achmat, February 2008).[42]

As noted previously, adherence counsellors were at the centre of the Lusikisiki HIV/AIDS Programme. Acting as clinic-based health promoters who represented the interests of the community, they were considered the glue that held the treatment system together. Adherence Counsellors were lay health workers, recruited from among HIV-positive community health workers who received training through workshops and onsite mentoring. Within a few months of their training they were able to manage all the key processes of running a primary HIV health care clinic including voluntary testing and counselling (VCT), user support, treatment preparedness, support group facilitation, arranging follow-up visits,

[42] Information from unpulished data by the University of Cape Town and MSF.

teaching ARV pillbox packaging techniques, addressing adherence issues, and collecting and reporting programme statistics.

Adherence Counsellors worked closely with other community leaders, volunteer community caregivers, support groups, adherence clinic committees, and HIV treatment activists. The fact that they did not wear uniforms was a statement about their being part of the community rather than a clinic hierarchy. At the same time they advocated for the rights of service users and participated in decision-making about health services provision. Adherence counsellors were held accountable for the number of enrolments per month, adherence to therapy (as indicated by viral load), and number of service users lost to follow-up every six months. The very low rate of lost to follow-up in the clinics (2%) was largely a result of the work performed by the adherence counsellors. While the critical role played by adherence counsellors was widely acknowledged by clinic staff and service users, the function is still not funded by the Eastern Cape Department of Health or included in its clinic staffing model.

The three central organizations engaged in the Lusikisiki HIV/AIDS programme had different motivations and agendas for entering into the partnership. MSF had an interest in improving capacity and access to ARV treatment in this rural, under-resourced community. The national DOH had been under fierce criticism both nationally and internationally due to their reluctance to provide universal access to HIV/AIDS treatment and was therefore keen to prove its ability to implement and manage a treatment programme. Finally, the TAC's agenda was to support the goal of universal access to cost-effective HIV/AIDS treatment for PLWHAA. Despite their differing goals and means to implementing the Lusikisiki HIV/AIDS programme, they each had the common interest of ensuring that the programme worked successfully.

As argued in Chapter 4, governance is a process of interaction between various interest groups. The alliances and interactions observed in the Lusikisiki

programme are central examples of the politics of governance. As Migdal argued in 2001, there are various actors and coalitions that struggle over gaining influence to have their opinions heard, and to have an impact on policy-making and implementation in the processes of governance, This was no less the case in Lusikisiki.

# Chapter 7: Social Mobilisation and the Dual Role of the TAC

The previous chapter included a discussion of the ways in which three members of the tripartite alliance formed to implement the HIV/AIDS treatment programme in Lusikisiki−a civil society organisation (TAC), an international NGO (MSF) and the Eastern Cape DOH. In particular, it highlighted the multifaceted character of CSOs and NGOs as they engage and agitate in their interactions with the state.

Central to this chapter is a discussion and analysis of the social mobilization tactics of the TAC employed through its treatment literacy programme. It focuses primarily on TAC's strategies with regard to the politics and practice of democratic governance. It will be argued that the TAC employed a dual role as it advocated for more accessible service delivery within a patient-rights framework, and how this patients-rights approach to social mobilization negatively impacted its relationship and effectiveness with all levels of the DOH. In combining the politics of engagement with politics of opposition, the TAC's relationship with the DOH resulted in antagonistic and uncooperative interactions. It is characteristic of an approach to democratic governance that both enjoys access to power while at the same time disenfranchising the community (Friedman and Mottiar, 2004).

## 7.1 Social Mobilization in the Lusikisiki HIV/AIDS Programme

AIDS 'denialism' fuelled the stigma and understanding of HIV/AIDS in South Africa, leading people to believe that ARV's were toxic and that ultimately poverty caused HIV/AIDS (Gevisser, 2007; Gumede, 2007, and Mangcu, 2008), believing that President Mbeki, a declared AIDS denialist, "was the key figure to break the silence on AIDS in South Africa during the 1990s" (Roberts, 2007). This rhetoric called for a well-organized social mobilization campaign if an ARV-based treatment programme was to succeed. AIDS myths, 'denialism,' and stigma were common in rural South African communities that had not been exposed to grassroots mobilization and treatment literacy campaigns (Robbins, 2004a; Steinburg, 2008). Social mobilization was a tool to inform communities about

alternative explanations for the spread of HIV/AIDS and to promote and encourage testing and treatment (TAC, 2006). In Lusikisiki, the social mobilization campaign initiated by TAC informed the community about its right to have access to health care and created openness to discuss the causes and treatment options for HIV/AIDS. It therefore contributed to a higher level of HIV/AIDS literacy which was central to the success of the Lusikisiki treatment programme. One adherence counsellor put it this way,[43]

> "At the beginning people were scared to take ARV's and they believed that when they were sick they would die…….at least now…we don't take much time preparing people for ARV drugs because they know. So it is helping, because most of the people are willing to take ARV drugs … because they know the side effects and all those things." (Interview with Thabo Ndola, March 2007).

The social mobilization campaign in Lusikisiki was carried out in surrounding communities as well as in clinics, hospitals, churches, community centres, and schools. Adherence counsellors and the TAC staff and volunteers played a critical educational role in the clinics promoting treatment literacy as the provincial ECDOH lay counsellors and nursing staff were still ignoring the causes and consequences of not treating HIV/AIDS (Interviews conducted in 2007 and 2008; Steinburg, 2008). Support groups, also led by the TAC, were central to expanding treatment literacy for PLWHA who were either on ARV therapy or preparing to do so.

> "Men and women who, under other circumstances, would have come no closer than to brush against one another on the town's main street, here exchange views on clitoral orgasms, and semen, and anal sex; proper conduct in matters of love, marriage, parenthood and nutrition; and, of course drugs. There has surely been nothing remotely like this in Pondoland's history. When a batch of people who have freshly tested positive join the support group, the discussion explodes into shards that disperse across every aspect of life" (Steinburg, 2008).

[43] Some of the Adherence Counsellors and my interviewees that I interviewed wanted to remain anonymous, so I will use psuedo names each time I quote them.

### 7.2 Promoting Treatment Literacy

Although people were scared to take ARV drugs in the beginning, their perceptions of the value of ARV drugs gradually changed during the life of the programme (Steinburg, 2008)[44]. Treatment literacy was an "understanding of the major issues related to an illness or a disease - such as the science, treatment, side effects, and guidelines – so that the patient can be responsible for their own care and will demand their rights when proper care is not available for them. The treatment literacy campaign…aimed at making available information that could help save lives of people living with HIV and their communities." (TAC, 2006)

> "The treatment project was a way for the TAC to show skeptics, particularly government officials, that ARV programmes could be implemented effectively, despite among other things repeated claims that patients would not take their medication in the required manner. It also put in place structures to buttress the treatment project – preparation workshops and a network of councillors who undertook home visits. It argued that this support was essential if an ARV programme was to be effective and criticised the government for not beginning this process, which it insists was essential to the ARV "roll out". The exercise was, therefore, a campaigning tool, and a demonstration of the role TAC could play in the "roll out", as well as a service" (Friedman and Mottiar, 2004).

Prior to 2003, ARV therapy was not available in the public health sector in Lusikisiki (Steinburg, 2008). Primary health care clinics were not accredited to distribute HIV/AIDS fighting drugs. With the implementation of the MSF HIV/AIDS programme, ARV drugs became available for the treatment of opportunistic infections in all 12 primary health care clinics (MFS and DOH, 2006; Steinburg, 2008). Most key informants interviewed for this study noted that people in Lusikisiki started demanding their right to treatment and access to health care services in general.

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[44] Jonny Steinburg, *Three-Letter Plague: a young man's journey through a great epidemic*. (USA: Simon & Schuster, Inc., 2008), has a discussion of the general perception of ARV drugs and HIV/AIDS treatment prior to and during the early days of MSF's arrival in Lusikisiki and surrounding areas.

> "The need to treat shingles illustrates by a lot of people visiting clinics for treatment is an example of how people in Lusikisiki are now aware of their right to treatment … Some sick people even know the name of the treatment they need for shingles … This also shows that the TAC are doing their job out there in communities" (Interview with Emmanuel Kelias, March 2007).

Prior to the introduction of the MSF programme in Lusikisiki, if a person had shingles, they would be given calamine (Interview with Nurse B, March 2007). According to many of my interviewees, most of whom are HIV-positive, it became understood from posters in the programme offices, that acyclovir was a more effective drug for shingles. Consequently, the TAC staff, volunteers, and adherence counsellors in Lusikisiki started informing people about their rights to acyclovir which resulted in a change in the medication used for shingles. (Interviews with the TAC staff, volunteers, and adherence counsellors).

Robins argues that " the hierarchical and authoritarian cultures of many public health facilities can create obstacles in terms of access to AIDS programmes, particularly in areas untouched by social mobilization and health activism" (2004a: 17). These obstacles had begun to be broken down in Lusikisiki, precisely because of the social mobilization of the community. For example, the introduction of *task shifting*, which involved the training and deployment of lesser trained health care workers such as nurses, nursing assistants, adherence counsellors, and community health workers coupled with appropriate delegation of duties under protocols reduced the workload of doctors and increased access to care.

> "Using a mixture of charisma and sheer slog, Hermann built a social movement and stationed its members in the clinics. A cohort of Adherence Counsellors recruited and trained by Hermann and put on MSF's payroll, did the lion's share of the AIDS work in the clinics. They performed voluntary counselling and testing, prepared patients for treatment, established support groups for antiretroviral users with the TAC members and volunteers, monitored the adherence of antiretroviral users to their treatment, and collected and collated data" (Steinburg, 2008).

The treatment literacy campaigns and community mobilization played a central role in the success of the Lusikisiki HIV/AIDS programme. Prior to MSF, there had been no organized psycho-social support and little, if any, hope of survival for PLWHAA (Steinburg, 2008). However, during the first three years of the programme, almost two thirds of the adult population in Lusikisiki went through voluntary counselling and testing and over 2000 individuals were on ARV therapy by late 2006 (Interview with Dr. Hermann, August 2006; MSF and DOH, 2006; Steinburg, 2008).

### 7.3 Modes of Mobilization

TAC conducted numerous workshops in which they trained treatment literacy practitioners (TLPs) and volunteers from organizations other than MSF such HACCO to educate and mobilize the residents of Lusikisiki and surrounding communities. Central to their approach was the disclosure of one's HIV status as a way breaking down HIV stigma in the community. The TAC is known nationally for its social mobilisation campaigns, including its communication means and modes. One such mean was wearing tee-shirts emblazoned with HIV-POSITIVE (Friedman and Mottiar, 2004; Robins, 2004a; TAC, 2006).

The TAC regularly went into communities to conduct marches and door-to-door campaigns. In January 2004, the TAC launched a massive door-to-door campaign aimed at educating poor residents in the Eastern Cape on HIV/AIDS (Interview with Portia Ngcaba, April 2008). Accordingly, the campaign began at the end of January and covered the Nelson Mandela Metropole, Buffalo City and the OR Tambo municipal area. These areas were also targeted by the Eastern Cape DOH for its ARV roll-out which was to be launched later that year in 2004. The door-to-door campaigns were about taking the fight against HIV/AIDS to where it mattered most, the poor living in the townships,

> "We wanted an outreach programme that would reach almost every infected and affected part of the province so as to reduce the spread of the epidemic… most HIV-positive people don't know their status

> and rights when it comes to HIV/AIDS. We want to educate people about their rights" (Interview with a TAC volunteer Nosiphelo Jwara, April 2008).

TAC volunteers frequently visited schools, clinics, churches, and other institutions in the community during their treatment literacy campaigns. In March of 2007 the TAC organized a community mobilization to advocate for a public dialogue regarding the newly developed South African HIV/AIDS National Strategic Plan (NSP). The mobilization took place in schools, clinics, a tea plantation, and selected villages over a 3-day period. The goal of this mobilisation was to encourage the community to participate in the dialogue about the NSP.

The successes achieved by these mobilisations was that they were often carried out through small TAC groups that were sent to targeted communities and villages. They would march through the community, singing songs of liberation with revolutionary lyrics and when approached by residents they would engage in a quick educative chat. Their singing and marching along roads attracted a lot of attention. While their tactics suggested a partisan political rally, Friedman and Mottiar noted that "TAC [was] not affiliated with a political party and members are said to support a variety of parties. TAC is a political movement, but not a party political movement" (2004: 43). The time spent in the community, particularly through door-to-door activities, brought TAC members and volunteers closer to the day-to-day realities of the people they aimed to serve.

One of the TAC's most publicly visible item was the tee-shirt with an HIV-POSITIVE logo. The widespread distribution of these tee-shirts around Lusikisiki was striking (Robins, 2004b). One informant explained the difference between wearing the tee-shirt in one of the larger cities in the Eastern Cape Province and wearing it in Lusikisiki,

> “I normally go down to East London. If I go wearing the **HIV-POSITIVE** tee-shirt I get looks from people ….Here they don’t recognize anything. They are living with it…That’s how I compare Lusikisiki and East London. People here they are just free, as if they don’t recognize you are part of them…It is a consequence of the programme here. They are more knowledgeable, people from around…People here used to believe in traditional medicine…because you’ll find that people were taken to the hospital at a very, very late stage. But now you can see that the conventional medicine is here and it’s working. And I think that what has motivated them is that people were dying here, but some did recover very well. So they have seen it” (Interview with Ntombekhaya Booi, March 2007).

There was a noticeable difference in peoples’ reactions when wearing the HIV-POSITIVE tee-shirt in rural Lusikisiki relative to urban East London. It is arguably the result of the social mobilization activities associated with the Lusikisiki HIV/AIDS programme where people were more knowledgeable and that there was less stigma associated with HIV/AIDS in Lusikisiki.

### 7.4 Fellowship and Advocacy

Nationally, the TAC was known for being an organization that provided unity and a sense of belonging for PLWHA. It is an organization not driven by self-interest, but rather self-identity (Friedman and Mottiar, 2004; Robins, 2004a). Most TAC informants interviewed emphasized the strength and hope the organization provided. What the TAC offered was a sense of unity, belonging, and giving meaning to life,

> When I’m back from the hospital, TAC came … So I got empowered and I joined TAC… TAC gave me a lot. TAC made me strong, saying this is not the end of my life. I will survive… (Interview with Dumisani Ntuli, a Former TAC Volunteer, March 2007).

When members from the newly established TAC branch in Lusikisiki attended a TAC march in Cape Town in 2003, they came back home to Lusikisiki motivated to engage in the local struggle believing that they were part of a national social movement (Robins, 2004b).

If a clinic did not give out any type of treatment due to various causes, patients would often approach the TAC for assistance. During the time I spent at the TAC office in Lusikisiki, I witnessed this on several occasions.

### 7.5 Relationship to the Community

Community informants reported that ARV drugs had a de-stigmatizing effect on the community, especially because they saw people treated with ARV drugs recover. Consequently, being diagnosed with HIV was no longer viewed as a death sentence. The TAC did experience challenges because of the history of AIDS denialism in South Africa, particularly when it was suggested that the government believed ARV drugs were toxic (Van Der Vliet, 2004; SANCO, 2007; Robert, 2007). One informant discussed how the TAC changed peoples' perceptions on ARV drugs in Lusikisiki as a result of disclosing their HIV status.

> "We know that ARV drugs are working, because we saw that she was sick and now she is better …So people see that what we are saying is true. Because we are talking about our experiences…We go to the schools and say I am living with HIV. I was sick. I had these problems, but now I am ok.' And then people are seeing that it is working…Although we had the challenge of misleading information…it lead to our people not knowing who to believe. But they know now…' I've seen X is taking ARV drugs and is healthy" (Interview with Asekho Manana, TAC Volunteer, March 2007).

Initially, community members in and around Lusikisiki did not understand the role that the TAC was playing in Lusikisiki as they were perceived as an anti-government organization with political motives.

> "They were angry with TAC. They said TAC, No! This is our government, we are voting for this government, why are you toyi-toying with our government? But then they saw the change. They saw that people in Lusikisiki were becoming alright, they were fit, they were healthy…that the ARV drugs were helping their families"

(Interview with Pindi Mkani, an Adherence Counselor, March 2007).[45]

"People didn't know anything …people thought that TAC was coming to throw over the government …They thought we were a political organization and also that we were anti-government. But then we tried to explain and explain, so that they could understand" (Interview with Thandeka Xaba, TAC Member March 2007).

Nevertheless, the TAC had been working in communities for years and the general perception of the organization began to change. Even though people did not understand the reason for the sudden appearance of the TAC in Lusikisiki initially, community members gradually began to understand what it represented and that its members were not anti-government. According to TAC informants, the movement eventually was accepted and welcomed in Lusikisiki.

Most people I spoke with were familiar with the TAC and its mission, people from the surrounding communities also came to the office asking for assistance on various community issues not just HIV/AIDS. School-age youth also visited the TAC offices, interviewing members as part of a school assignment. Many ordinary citizens I spoke with assigned much respect to the TAC for the changing perceptions about HIV/AIDS and related social issues such as rape and gender-based violence.

### 7.6 TAC and Community Empowerment

According to some informants, the TAC empowered many Lusikisiki community members by educating them about their rights and ways to impact local governance policy and practice with regard to HIV/AIDS.

"People now know that they have a voice and that it should be heard. Anything that is going to be changed, a change of policies, they know that they've got rights to discuss and be part of anything that is going to change" (Interview with Thandeka Xaba, a TAC member, March 2007).

[45] Not her real name

Informants also noted that the Lusikisiki HIV/AIDS programme had changed relations between the state and civil society in Lusikisiki, “the community previously had no reason to get together and fight for something in the environment …Then they got shaken up by HIV/AIDS ... It was an opportunity, I think, to bring people together” (Interview with Xolani Zulu, a TAC Volunteer, August 2006). The implementation of the Lusikisiki HIV/AIDS programme created a context in which the community had reason to unite around the common causes of access to ARV drugs and the right to basic health care services beyond HIV/AIDS. Friedman and Mottiar argued that TAC’s grassroots tactics offered community members an opportunity to be active rather than passive citizens.

> “Certainly the level of grassroots participation in TAC does suggest that it is doing far more than providing a vehicle for people concerned to find medical relief from a deadly condition– although even that may be a contribution to empowering its members since it enhances their technical knowledge of the virus, enabling them to be more active citizens: “If they go to a clinic with herpes or thrush they know what to ask for” (2004: 51).

**7.7 Challenges to Social Mobilization**

The TAC had been driving ‘globalization from below.’ Its grassroots mobilization efforts attracted international solidarity and support as it fought the big pharmaceutical companies for fair pricing, and getting the South African government to commit to rolling out access to ARV therapy. Their cause straddled local, national and global spaces, hence partnerships developed at all levels (Robins, 2004a). TAC deployed some class-based political tactics that were, in some cases gender biased (Friedman and Mottiar, 2004). Although a self-proclaimed grassroots movement, it was founded and largely driven by elites such as Zackie Achmat, a college-educated South African activist; Mark Heywood, executive director of the AIDS Law Project and chairperson of the South African National AIDS Council (SANAC); Nathan Geffen, a computer

science lecturer at the University of Cape Town; Sipho Mthathi, coordinator of the Diversity Project at South African Institute of Race Relations; and Hermann Reuter, a medical doctor and founder of MFS programme in Lusikisiki.

### 7.8 Politics of Class

A number of informants confirmed that they knew people in high positions in Lusikisiki that were on ARV drugs including church ministers or pastors, but who were hiding their HIV positive status. It appeared that the professional class in Lusikisiki, teachers, church ministers, and nurses were the ones most unwilling to disclose their HIV status. Why was this? Some argued it was due to the targeted messages to the poor and disenfranchised in the community.

> "Interviewees repeatedly stressed that more was at stake for people at the grassroots than the hope of receiving medication. Many noted the sense of hope, efficacy and self-worth which people drew from TAC. "TAC approaches HIV differently. It talks and teaches positive living, that this illness is not a sin – life is not wasted or less valuable, it must go on. TAC is an organisation for the people, it works directly with people –look how closely it works with support groups like ours, people who come to us are the poorest of the poor, those with no resources, education, information- that is why they come to TAC meetings, as well as in the hope of getting treatment" (Nomsa Nkosana, a Grassroots Activist, 2004).[46]

Clearly, the TAC focused its mobilization efforts on the poor and socially marginalized in Lusikisiki. According to Robins (2004a), this focus was due to the urban character and membership base of the TAC (Robins 2004a), Although little research has been conducted on TAC's social mobilization efforts in rural areas, my observations have led me to believe there are similarities between urban TAC strategies and those employed in Lusikisiki.

Community mobilization activities occur during the day and most often mid-week when they are more likely to encounter the unemployed, often women, or school leavers and out-of-school youth. As noted previously, TAC members are

[46] Not her real name.

predominantly poor, black, and young. Women outnumber men, young outnumber old, and about 80 percent are unemployed with low educational attainment (Friedman and Mottiar, 2004). This reality reinforces the apartheid view of HIV/AIDS as an epidemic of race and class (Robins, 2004a).

This class-based mobilization could be deemed relevant in the context of Lusikisiki as there is often a large divide in the policy agenda of elites and the 'grassroots.' As such, it is necessary to find avenues for all groups in a community to be heard if there is to be true participatory governance in policymaking and practice. TAC's mobilization strategy in Lusikisiki made a significant contribution in this regard. The TAC's contribution to participatory governance was achieved largely through its mobilization of the traditionally marginalized and empowering them through education and increasing knowledge of HIV/AIDS risks and treatment options.

### 7.9 Gender and Power

> "Almost every time, people that are disclosing are women. There are few men. Some of them they are still difficult to understand, they just deny…Women are stronger. And women are the people that stand up, stand up and fight for their rights. So always men are after women (Interview with Akhona Ntsabula, a TAC member).

From my research, more women disclosed their HIV status in Lusikisiki then men. Robins suggests that "patriarchal attitudes are likely to continue to be a serious obstacle to AIDS prevention and treatment programmes" (2004a). As one Lusikisiki informant observed;

> "What we have learnt is that cultural backgrounds are still working in areas like Lusikisiki. Because there are still people that are not understanding the issue of using condoms, they just say "no, they can't eat sweets with their paper' … They believe in these things like 'if you sleep with a virgin, HIV can go away'. So we have to change their minds. So the cultural background is still there…they can tell you that they have many wives…6 or 8 or 13. They are telling you it is their culture. And if you tell them about the condoms, they say

> ‘hey, how can I get this if you say I must use a condom,’ It is difficult to work in these areas” (Interview with Nombeko Gqamane, a TAC member, November 2006).

In Lusikisiki there were still many men with more than one wife and these men believe it is their prerogative of whether to use a condom or not; in many cases, it does not happen. According to Friedman and Mottair, another reason for men’s reluctance to participate in prevention and treatment programmes was that they feared the stigma of living openly as an HIV positive person (2004). Furthermore, it was believed that the dominance of women’s involvement in the TAC had a stifling influence on male participation.

The TAC in Lusikisiki had an entry point for women (gender desk) that assisted many local women with cases of rape, domestic violence, and abuse, “women come to TAC to seek support and report their cases of abuse” (Interview with Akhona Ntsabula, a TAC member, November 2006). The TAC often used its influence to get these cases reported to the police and followed-up the cases in court. The gender desk changed the discourse from talking about rape ‘victims’ to rape ‘survivors’ and established support groups for the survivors.

> “Now, people are empowered. They can be able to talk about HIV status, they can be able to say I’m a rape survivor…Because they’ve been in a support group, and I think that the support groups are really empowering the people… Here in Lusikisiki, there is a high rate of rape. But through the community mobilization that we do, people now are able to understand that you cannot just keep quiet. You can at least go to the police and report the matter…Because we’ve got cases where people can just decide to take it as a family matter and keep quiet about it. At least now, through the awareness that we are doing, people are coming forward and reporting cases” (Interview with Akhona Ntsabula, a TAC member, November 2006).

TAC at the national level has been criticized for having a male dominated leadership structure despite the predominantly female membership base. Nevertheless, at the grassroots level, it has provided women with leadership opportunities (Friedman and Mottiar, 2004). Although not surprising, the TAC in

Lusikisiki did contribute to women's empowerment through their active participation in the organization. Like most South African institutions at the time, TAC was far from achieving full gender equity, in spite of the evidence that women were much more likely to be HIV-infected than men (Department of Health, 2002). Statistics show that women between 15 and 30 years are more vulnerable to the virus than any other group. In the TAC Lusikisiki branch there are far more women than men. While attendance at branch meetings and events differed from branch to branch in numbers and gender distribution, from my observation I estimate that more than 75 percent attending were women. Lusikisiki women, who were subjected disproportionately to domestic abuse and violence, coupled with increased exposure to HIV, provided an added incentive to participate in the TAC.

### 7.10 The Duality of TAC Strategies

The TAC played a critical role in Lusikisiki through its social mobilization tactics in educating the community about HIV/AIDS risks, spread, and treatment. As a result of this social mobilization many people were tested for HIV and subsequently enrolled in the ARV therapy programme. It can be argued that this is a service delivery role delivered through the 'politics of engagement.' On the other hand, TAC also employed an activist, rights-based approach to social mobilization using what Habib and Kotze (2003) labeled as a 'politics of opposition'. The balancing of these two approaches was largely acknowledged as the key to the TAC's success.

> "In the Eastern Cape, how it has worked for TAC to be quite recognized is the fact that they are having those two balancing, and at the same time knowing how to adjust when you come to the NGO level and also knowing how to adjust when you move away from the NGO level to being a social movement so that you can accommodate all spheres" (Interview with Mbulelo Kutu, 2007).

The TAC had goals that they wanted to achieve on behalf of PLWHAA in South Africa and often worked with governmental agencies to reach these goals as a deliverer of direct services. However, when government became complacent or

slowed down progress, the TAC engaged in activist activities, taking on the role of a social movement.

> "I think the problem is they [DOH] are still taking TAC as someone who are just toyi-toying…They are not seeing that other side, doing treatment literacy that are helping people, they're taking us [TAC] as we are only fighting government…When they see TAC, they see people who are fighting with government. They just don't want to sit down and see what is really happening" (Interview with Thandeka Vinjwa, a TAC Volunteer, November 2006).

It could have been difficult for government officials to engage with a CSO that on one hand partnered with the DOH while simultaneously opposing official government policies on the other. It was for this reason that officials in the Eastern Cape DOH withheld information such as programme statistics from TAC members.

> "The TAC has adopted a political strategy that always collaboration with government rather than conflict…TAC responded first with research and rational argument, and resorted to litigation and protest only after this failed to bring about a change in policy …As a result of this conflict over AIDS policy, the TAC has been inaccurately depicted as 'anti-government.'" (Heywood, 2005: 58).

In spite of this dual role, the TAC was considered an important source of support by people working with PLWHA in the health sector. One informant from St. Elisabeth Hospital indicated that it was by toyi-toying that the TAC had its greatest impact on ensuring service delivery.

The TAC struggled with these two faces within the context of donor support. Some donors choose to only fund their service delivery side, conditioning the support to not be used for activist activities. The Treatment Literacy Programme was particularly popular among the donors. This presented a problem for the Eastern Cape TAC as it saw its dual role as being integrated and inseparable. For example when the TAC assisted a local public hospital in the roll-out of an HIV/AIDS treatment programme where they would be doing patient mobilization and treatment literacy. The government moved frustratingly slow which called for

an activist role to put pressure on the DOH to initiate the roll-out. (Interview with Ngcaba, April 2008). When the DOH did not include the TAC in key decision-making processes, it fueled the use of *'toyi-toying'* to ensure its right to participate.

### 7.11 The 'Old' versus 'New' Struggle

According to Midgal (2001), an organization's ability to influence behavior and policy depends on its capacity to generate symbols to which people can attach themselves. The TAC managed to generate such symbols. They used social mobilisation to attract community attention and support for its 'rights to health care' goal much in the same way that the anti-apartheid movement made use of revolutionary songs and slogans in its struggle against apartheid. These songs and slogans were effectively used by the TAC which used the same symbols for its advocacy for universal access to HIV/AIDS treatment. The melody of the songs was the same but lyrics were changed to fit the HIV/AIDS struggle (Robin, 2004a). The songs from the old struggle were used in what was labeled 'the new struggle.' These revolutionary liberation songs and slogans generated a genuine interest in communities where people would come out of their houses and turn up in the maize fields to find out what the buzz was all about.

> "There are so many issues around HIV, which most of the time we used to feel that we are not free when it comes to being in South Africa as a democratic …That's why we feel that we are in a revolution when it comes to HIV and AIDS…it's a wake –up call to the people who are the policy makers and also to the people who are responsible for the service delivery and for seeing that the constitutional rights of the people are not being violated. That's why you'll find our songs is more revolutionary, because ….we are in struggle when it comes to HIV, up until …there is universal access to ARV treatment." (Interview with Ntombenkosi Makubalo, a TAC Volunteer, November 2006).

This use of the anti-apartheid songs and slogans provoked some government officials as they believed these songs and slogans triggered mixed memories of the apartheid struggle (Interview with Ntombenkosi Makubalo, November 2008).

The songs and slogans were particularly poignant in the former Transkei (Eastern Cape), a homeland under apartheid. The Eastern Cape is an African National Congress (ANC) stronghold from which many anti-apartheid political leaders heralded.

From my interview, it appeared that the Lusikisiki TAC members had not calculatedly used these liberation songs and slogans for their specific content but rather believed that the association with anti-apartheid tools would be an effective way to attract the community in their social mobilization campaigns. In contrast, provincial level public health officials were very much aware of the effect these liberation and revolutionary tactics had on many former freedom fighters within the DOH.

In sum, the community mobilization efforts of the TAC focused on the poor, unemployed, and otherwise marginalized populations in Lusikisiki and its surrounding areas in spite of HIV/AIDS being an epidemic that crossed traditional class boundaries. Furthermore, the female dominated presence in programmes and mobilization contributed to the TAC being perceived as an organization of and for women which had consequences for male participation in the education and treatment aspects of the programme. Nevertheless, the Lusikisiki TAC has provided an interesting case study of participatory governance at the local level through a rights-based social mobilization effort. The Lusikisiki TAC effort has illustrated how a social movement (Friedman and Mottiar, 2004; Heywood, 2005) took up the role of a service-delivery organization while continuing its community mobilization function with revolutionary songs and slogans from the anti-apartheid struggle.

## Chapter 8: Messiahs and Pariahs? Cultural Scripts and Liberation Rhetoric in Lusikisiki

By the mid-2000, the *Mèdecins Sans Frontières* (MSF) and the Treatment Action Campaign (TAC) had a formidable following in Lusikisiki. They had literally taken the place by storm and were on the lips of everyone. Their leader Dr. Herman Reuter was known to rural villagers and his name reverberated across the hills and in the valleys of Pondoland. He was viewed as a kind of messiah, a barefoot doctor with foreign connections and powerful medicines who had come to save a people weakened and dying as a result of HIV/AIDS. This image of Dr. Herman Reuter as a messianic figure and his organisation as a potential saviour of thousands fits a well-known script of political mobilisation in the Transkei. Dr. Reuter and the TAC seemed to slot into a familiar cultural script of messianic leadership and even millenarianism in a region.

Over the previous century numerous prophets rose in the Eastern Cape with messages of salvation for the poor and downcast. In most instances some form of threat to the survival of the community was at stake. In the 1850s, as we will see, it was Nongqawuse who predicted the Xhosa nation would be destroyed if they did not kill their cattle, and there was a real possibility of that occurring due to bovine lung sickness and drought. In the 1890s during the Rinderpest epidemic, which like lung sickness threatened cattle, there were new prophets who predicted the end of the world as people knew it and the rise of a new order. In the early twentieth century other prophets arose; Nontate at the time of the 1918 influenza epidemic and Wellington Buthelezi in the 1920s. All of the prophets listed here had visions that connected the rise of a new order with the destruction of whites and colonialism. In the case of the last two, the saviours of the world would not be new people from the realm of the ancestors, but African Americans who would arrive on the shores and start taking over the government of the African people. These latter visions and predications were influenced by

Graveyism and its message of self-help and of uniting all black people around the globe.

In this chapter I reflect briefly on these stories of prophetic leadership and social change and relate them to the case of Dr. Herman Reuter and his presence in Pondoland and Lusikisiki in the mid-2000s. There were important ways in which his campaign and that of MSF and TAC resonated with these earlier forms of struggle and interpretation of the world. Although Dr. Herman Reuter was neither black nor spoke with the bible, his message was radical and transformative in the lives of a sick and ailing in this rural community. Within the popular imagination there is no doubt that he was seen as a saviour of some kind, a person with external connections, powers and knowledge that would change people's lives. The fact that Herman was white did not mean that he fell outside the scope of local millenarian narratives. In fact, throughout the history of the region, locals have supported people of any colour who stood against those who oppressed them and made them ill. In the1850s the Russians were so popular that, despite being white, children were named after them. Their popularity derived from the fact that they defeated the British in the Crimean and thus became local heroes. Similarly, during the struggle against apartheid there was a belief that communists from China would bring weapons and supplies through Port St John's and take up leadership positions. The idea that 'cargo', meaning goods, things and commodities, could come into the region from overseas for the assistance of local communities was well-established.

The argument made in this chapter is not that Dr. Herman Reuter was conceived as a foreign prophet who would change the world in an instance with secret magical substances which were imported from outside the territory and the country. It is rather to suggest that the cultural history of resistance in the region made such a narrative possible and that Dr Herman was seen as prophet of some proportion. The religious affiliations of the TAC supporters in Lusikisiki are discussed as I argue that most supporters of the movement were not only

women, but Christians and that prayer and religious ritual was associated with their cause which created a sense of unity and common purpose.

The chapter also deals with the growing opposition to President Thabo Mbeki and especially to Health Minister Tshabalala Msimang in Lusikisiki during the mid-2000s. By denying people pills to treat HIV/AIDS, local resistance to particular figures in the ANC grew within the rural areas. It is interesting that the narrative was not one which rejected the ANC, it simply rejected certain individuals and aspects of the rural party's policies and programmes. In fact, as we will see in the next chapter, while activists criticised the food and nutrition as a means to address HIV/AIDS arguments of government, they embraced the message that poverty was one of the important causes of the disease and that the state should provide them with better food and nutrition in their communities.

The key point of this discussion of resistance is that it became focused on the person of the Health Minister, and secondarily, that it was embedded in the cultural grammar and forms of the anti-apartheid struggle. This is not surprising since some of the leading South African TAC activists like Zakie Achmat were leading figures in both liberation movements. This chapter argues that the way in which liberation songs, in particular, were adjusted and adapted was a key part of rural activism in Lusikisiki in the mid-2000s.

I have suggested that local knowledge and cultural forms are critical to the understanding of HIV/AIDS and the responses to it at the local level. In this chapter I focus on local political traditions and cultural idioms and how they intersect with national and even an international discourse of resistance and rights claims in the struggle against AIDS denialism. The chapter reveals this through the lens of contrasting representations and perceptions of Dr Herman Reuter and Dr Tshabalala-Msimang in the HIV/AID struggle in Lusikisiki.

**8.1 Prophecies, Politics and Messianic Figures**

In the 1850s, the young Xhosa prophetess, Nongqawuse, had a vision where the white settlers who were waging war against the Xhosa and stealing their cattle would be driven into the sea if the Xhosa didn't killed their sickly cattle and burn their fields and granaries. The vision of Nongqawuse was given to her by the ancestors who stated that this was the only way for the Xhosa to be saved from the tyranny of colonisation. Nongqawuse' s vision developed a strong following amongst King Sarili people and through them was spread to other Xhosa chiefdoms until the cattle killing movement had wide support across the region. There were believers and non-believers, the believers followed the prophetess and killed their cattle and destroyed their crops, while the non-believers refused to decimate their herds and risk their crops. They hung onto their herds which were dying from lung sickness and their fields that were parched by drought. Many felt that their world was being turned upside down anyway and that it would make little difference if they killed their cattle rather than allow them to die of unnatural causes. There was a lot of suspicion that the ancestors were angry and that action was needed to bring equilibrium back to the land. In this context many more killed their cattle than those who did not and the movement grew in popularity throughout the mid-1850s.

At various points it was declared that the moment had arrived when the new people would rise and the whites would be driven into the sea. Each time that the prophecy failed to come to pass, the failure was blamed on the non-believers, whose lack of action and betrayal of the cause of the Xhosa people was stifling the rise of the new world. Throughout the 1850s the believers persisted with their seaside séances, but to no avail. The world did not change in the way they imagined it would. In fact, with no cattle and crops on which to survive, the believers became beggars in their own land and eventually gave themselves up to the colonialists as a defeated people (Peires, 1989; Mda, 2000; Crais 2001).

Seventy years after Nongqawuse predicted that whites would be washed into the sea, another Xhosa prophetess, Nonteta, emerged around the time of the influenza epidemic of 1918 which claimed the lives of 250 000 people in South Africa. It was a bit like the AIDS epidemic in the way it took lives of the poor in rural communities. Nonteta claimed that she had died and been resurrected by God with the mission of converting Africans to Jesus Christ. She claimed that she had seen that American Negroes would come to South Africa and cut the throats of white South Africans, thus leaving the country to the African Christians who followed her and believed in the apocalypse. She prophesised that Judgement Day would come as predicated in the bible and that black Americans would arrive to liberate the country and free the people. She encouraged children to sing hymns announcing the coming of a new era and confronted the government by seeking support for her vision in government schools and institutions. She was locked up in a psychiatric hospital in Pretoria and later died of liver cancer in 1923. Nonteta was one in a long line of Xhosa prophets and prophetesses who have taken drought and illness as a sign that the old colonial order will be washed away in an apocalyptic event and a new order would rise up from the ground to save the lives of people and secure their physical and social health (Vinson 2012; Edgar, 2014).

If the frequent divisions of Xhosa land between believers and non-believers offers some point of comparison to the social splits in Pondoland with the arrival of MSF and the TAC in Lusikisiki, then the most apt historical comparison for Dr. Reuter is probably the mysterious Dr Wellington Buthelezi, who operated across the Transkei as a healer and prophet in the late 1920s. Like Dr. Herman Reuter, Buthelezi was not a local. He originally came from Zululand but had spent some time in Alice at the Lovedale College in 1923 where he mingled with local African elites. He was trained as a traditional healer but claimed to be a medical doctor with a degree from the United States of America (USA). Buthelezi, who was influenced by the teachings of Marcus Garvey, was a preacher who travelled around the rural districts of the Transkei with his message that Europeans were

‘witches’ and that African Americans would come to liberate Africans in the Transkei by setting up an African American government in the country. Many commented at the speed with which Buthelezi was able to capture a crowd and how quickly entire districts had shifted to his way of thinking. Buthelezi also likened British colonisation to the way in which the Israelites had been enslaved in Egypt. He said that just as the locusts had decimated the fields of the Egyptians so too would locusts come to the fields of the oppressor and that local people would then know that the apocalypse was near, that the new world was about to dawn (Vinson, 2012).

Some of the followers of Buthelezi declared that they, like him, were already Americans and that they would start to create their own churches and schools. This movement was encouraged and during the late 1920s Buthelezi established more than 180 schools and churches in South Africa with the assistance of the Garvey movement in the US. The state then clamped down on him and his followers and he was banned from visiting or preaching in the Eastern Cape in 1930. Buthelezi had mobilised thousands, but he was also a charlatan too because he persuaded the rural poor to give him funds which he used to enrich himself. Robert Vinson (2012: 118) reflects on his legacy;

> …his myth self-sparked a myth of liberation from America that never came. And yet it led to a political movement that reverberated throughout the Transkei for several decades. He employed legends and past prophecies of African American liberators to construct millennial solutions to the suffering of Africans. He mobilised rural Africans as a group…..Buthelezi’s delusional claims can be seen as a master work of political genius.

As in past scourges in Pondoland, the arrival of HIV/AIDS in Lusikisiki brought enormous hardship and pain to households and families who were confronted by forces which tore their lives apart and killed their husbands, wives and children. The cause of the hardship was not always known but the fact that bad luck and death was sweeping the countryside was not a mystery to anyone. In this context it is not surprising that many viewed Dr. Herman Reuters as a messiah. He was a

man with passion and a vision which he firmly believed would change the lives of the rural poor. He articulated his vision in a way which suggested that the African National Congress (ANC) government had sold short the people of Lusikisiki. There was also something quite miraculous about his story of ARV drugs, drugs with the power to drive back the threat of death and provide prolonged life to those with infections.

In one sense, Dr. Reuter's arrival in Lusikisiki created a dividing line between believers and non-believers in much the same way Nongqawuse did in the 1850s. He offered the rural poor residents of Lusikisiki a choice, either they continued to adhere to the government's prescription of improved nutrition to halt the spread of HIV/AIDS or they could enrol in his clinic, get tested, and start a regimen of ARV therapy as the means to save the lives of infected community members. He came as an internationally renowned doctor with the backing of a prestigious European organisation with considerable resources and expertise, and with close connections to the politically influential South African TAC. The personal charisma of the man and his endless energy and willingness to locate his operation within Pondoland gave him a high profile. People wanted to see him in action, addressing villagers and implementing strategies that would change the lives of the rural poor, especially women, who were amongst his most avid supporters.

While the history of prophetic movements and the stories such as that of Wellington Buthelezi and other healers of various kinds might seem far removed from the events that unfolded in Pondoland in the 2000s, there are interesting parallels to be drawn between the meteoric rise of the MSF and the TAC and some of the movements discussed above. The efficiency with which MSF and the TAC were able to set themselves up in Lusikisiki with the immediate presence of key personnel on the ground from the onset, made the clinic's impact substantial from the start. The fact that Dr. Reuter brought his expertise and resources from abroad, with important South African connections beyond

those found locally, could be compared to that of Dr. Buthelezite and other movements occurring in the Transkei over time that claimed power and authority with foreign connections. The treatments and support that MSF and the TAC offered was not a local medicine comprised of local herbs mixed together with other substances, it came from outside the community (from America). The treatment was clear and straight forward, these imported drugs would save lives.

It became increasingly less difficult to understand and appreciate how ARV drugs worked and also how the state was neglecting its responsibility to the people by refusing to supply these drugs on a community-wide basis. A prophesy of sorts emerged, come to the clinic, receive ART, join the TAC, and save your life. There were no visions, no locusts moving through the fields, or whites or government officials being driven into the sea, just a clear message of survival connected to an internationally funded programme.

A point of departure from other movements cited above was that that no reference was made to the bible. It was not an act of God that would save people but a combination of social mobilization based on human rights and the science of pharmacologic interventions. In the 2000s, the liberation struggle songs and rhetoric remained strong in the Transkei countryside and it was to these traditions rather than to those of the bible that the TAC turned to when it confronted the government's HIV/AIDS policy in the rural areas. Just as religion provided a vehicle for earlier efforts to imagine a new beginning, so to the rhetoric of the liberation struggle offered the TAC a narrative through which to structure its community mobilization. In this chapter I discuss how AIDS activism was politicised in Lusikisiki in the mid-2000s when the TAC was at the height of its popularity in the region. During that time, I attended many of the meetings and rallies in Lusikisiki and moved around with the core group of doctors and activists. It was during these activities that I observed how Dr. Reuter was viewed at the village level, like a messiah who had come to save the people from death and illness, and how the community responded to his message.

When I entered the villages that comprise Lusikisiki at the end of Dr. Reuter's tenure at the clinic, people spoke of him in a very personal way. They spoke of the roles of other organisations and NGOs, but singled out Dr. Reuter's role as a personification of the good work that had been achieved in their community. People described his extraordinary level of energy and compassion for the plight of the rural poor compared to other medical doctors in the rural areas. They sung his name in songs and celebrated his contribution long after he left. He represented a shaft of light in the everyday lives of communities that were struggling with HIV/AIDS at that time. Whether his contribution can be fully equated with some of the prophetic figures mentioned earlier is a matter of debate, but there can no doubt that his presence and impact elevated him in the imaginations of the rural poor with whom he interacted.

**8.2 Christian Soldiers: Religion and AIDS in Lusikisiki**

While in the modern world there appears to be relatively little relationship between religion and public health policy with regard to contagious diseases, HIV/AIDS has proved to be an exceptional case. According to Kenneth Overberg, the HIV/AIDS epidemic has challenged the world's religions to respond to a complex set of ethical and societal issues (1994). Given the fact that some religions view HIV/AIDS as a punishment from God, global and community response has been a complex undertaking.

Against this backdrop, it is not surprising that the formation of the Treatment Action Campaign (TAC) on December 10, 1998 (International Human Rights Day) called upon religious leaders, initially the Anglican Church, to be an integral part of its mobilization efforts, "...a group of 15 people protested on the steps of St. George's Cathedral in Cape Town to demand medical treatment for people living with the virus that causes AIDS." This protest that started at the doorstep of the Anglican Cathedral provided a platform for the relationship between the TAC and the Christian church that was to follow. In August 1999, the TAC held an

inter-faith service at St. George's Cathedral in Cape Town, where Jewish, Muslims and United Reform Church leaders called on the government to provide moral and political leadership and financial support in the fight against the HIV/AIDS epidemic.

While the TAC has had a significant impact on many fronts, the HIV/AIDS message within a religious setting had many religious groups reticent about being seen as associating too closely with this rights-based social organization, the reasons were varied. One reason that I was provided by a church leader from Lusikisiki was thusly stated,

> "It could be because church leaders know that such a high profile organisation as the TAC will in-turn be the face of their local church's ministry should any warmth of a relationship occur. The stakes are very high." (Anonymous)

Regardless of the concern that the TAC would take over the social mission of the church, it attracted willing and able individual volunteers from a variety of religious persuasions, the largest being Christianity. It was therefore not surprising that most, if not all of the TAC staff volunteers in Lusikisiki came from a Christian background and got to know about the TAC from church services. TAC gatherings always began with a prayer; in fact, the first thing on the TAC agendas was a brief sermon and prayer from a pastor or reverend, a church leader, or respected community elder. It was also the case that the TAC in Lusikisiki often was invited by a church leader to talk about its work and the human rights agenda it represented. Additionally, the TAC gave workshops to church workers. In a workshop I attended, I interviewed Siphokazi Mabhena. She had this to say,

> "When I joined my support group in my church, I felt as if a big load was taken from me. I felt free and happy for the first time since I been tested positive... Before I joined my support group, I wanted to die... I thought it was better to die than to live with HIV. People will look at you and make bad comments and no-one will want to touch you anymore. I felt as if I was already dead... although I still looked

> healthy... I am still afraid of having to live with stigma, people's tongues behind my back and the feeling that I don't belong anymore to society. But we talk about our fears and feelings openly in my support group. Every week I walk and I feel strong I am very happy that we meet in the church. It makes me think that God is also a member of my support group" (November 2008).

I was touched by Siphokazi Mabhena's story and was surprised that most of the support groups that she knew of met at churches in the closest village. Some church leaders were happy to sponsor support group meetings at their church while others were not as welcoming. In one of my many interviews with Dr. Reuter, I learned that some pastors still preached that HIV/AIDS was a punishment from God and they therefore did not want support group meetings of HIV/AIDS victims in their churches. There were also church leaders that taught their members that belief in God that faith alone would heal them. It has been suggested that church leaders who believe that "HIV/AIDS is a punishment from God"[47] had a deeply confused theology coupled with a rejection of science. These church leaders would say of an HIV-related death, "this was God's will." Such church leaders and pastors do not want their members to have anything to do with the TAC and yet in a story related to me by Dr. Reuter, he reported that these same pastors and leaders turn to ARV drugs once they test HIV-positive.

> "I have an ARV patient who is a pastor. He is doing well, has put on weight and has had no side-effects. He is a pastor of a church in which no-one knows about his HIV status or his participation in the ART programme. His message to his congregation is consistently that, with faith in God, there is no need for anyone to turn to ART."

### 8.3 Liberation Rhetoric: The Power of Song

> "Any musical innovation is full of danger to the whole State, and ought to be prohibited; when modes of music change, the fundamental laws of the state always change with them" (Plato, *The Republic*, as quoted in Byerly, 1998).

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[47] To read more on HIV/AIDS as punishment from God, I refer you to Ronald Nicolson (1996), *God in AIDS? A Theological Enquiry*, London: SCM Press LtD.

As Plato once noted, music at times carries meaning that goes beyond the purely musical level and enters into the political sphere. Among many other African states in their struggle for independence, South Africa was the latest notable example of the politicization of music. Since the moral outrage at the injustices committed by the apartheid government became part of Western pop culture through songs such as 'Biko' by Peter Gabriel, campaigns such as Sun City organised by Little Steven (Ullestad, 1987), and the successive Nelson Mandela concerts at Wembley Stadium in London in 1988 and 1990 (Garofalo, 1992), songs played a vital role in putting political pressure on the apartheid regime.

Anthropological and historical accounts, particularly during the African liberation struggles in pre-modern days and the more recent days of liberation struggles, deeds of heroism, moments of joy, sorrow, and prosperity, have been expressed through artistic venues and included songs, dance, story-telling, heroic recitations, and similar narratives (Spiegel and McAllister, 1991). In addition to conveying religious, cultural, and socio-political messages, were 'maps' of individual and communal experiences (Vail and White, 1991). Hence, Willie Peacock as quoted in Carawan and Carawan writes;

> Through songs and dance a people are able to share their burden, triumph, sadness and gladness of heart. They sing songs about the common oppressor or exploiter ... songs can be used to draw people together and unite them in one common aim, goal and purpose (1990).

Dave Matthews notes that, "singing is something that is hard to ban" (*Amandla*! 2003). Alton Pollard III also purports that, "in point of fact, no amount of government resolve could quell the insurrectionary power of songs" (1999). Indeed songs and music help communicate certain causes and are catalysts for raising awareness. Songs, music, along with slogans, *toyi-toyi,* and prayer have helped the TAC to meet and broaden its objectives and achieve its goals in the battle against HIV/AIDS in Lusikisiki.

Liberation songs and music in general are not unique to a particular people, culture, country, or era. For as long as inequality exists between people, those who feel oppressed and marginalised will find strength and aspiration in songs and music as an outward expression of their feelings of alienation. The lyrics, messages, and musical beat may change over time, but the aims and purpose of music as medium remain the same: better living and working conditions without discrimination for people based on gender, race, or material status.

Over time and political leadership, South Africa's approach to the fight against the HIV/AIDS epidemic has been criticised at home and abroad. In 2000, President Thabo Mbeki and his Minister of Health, Mantombazana Tshabalala-Msimang, sparked outrage by openly questioning the link between HIV and AIDS. During this time, AIDS activists welcomed South Africa's long overdue plan to revamp its HIV/AIDS policies and programmes. The first five-year HIV/AIDS plan in which Ms. Tshabalala-Msimang played a central role, received its fair share of controversy.

A major criticism, mostly by the TAC and its allies, was targeted at the plan's approach for the purchase and distribution of ARV drugs. Besides her pivotal role in the five-year plan, Ms. Tshabalala-Msimang was vilified for her now-famous promotion of beetroot and vegetables as the preferred treatment for HIV. It was in this context that the TAC adopted liberation music and songs, slogans, and *toyi-toyi* to mock Ms. Tshabalala-Msimang, and President Mbeki. The focal point of their mockery was denialism that HIV led to AIDS and their continued resistance to make ARV drugs available to the infected population.

The TAC in Lusikisiki adopted tactics from Africa's oldest liberation movement – the ANC, in its mobilization campaign for access to HIV/AIDS life-extending drugs. Once a comrade in arms in the liberation struggle, Zackie Achmat was both a member of the ANC and the founder of TAC. As a former anti-apartheid activist who figured prominently in the gay and lesbian community, he

subsequently re-aligned himself with his former anti-apartheid activist friends in the battle for justice and parity of access to ARV drugs and treatment for all infected South Africans. "The TAC sings modified freedom songs with HIV/AIDS replacing apartheid as the enemy and ARV drugs replacing AK47s as weapons of defence" (Cullinan, 2002).

In a uniquely South African context, the TAC led the struggle for equal access to HIV/AIDS medications and treatment; for evident-based HIV/AIDS policies and programmes; and for needed improvements in the delivery of health care services by making extensive use of liberation songs and music. Music is a powerful medium for communication in the African culture and featured prominently in the liberation movement. To an African, songs and musical rhythm are not luxuries but are integral to heartfelt communication.

The urgent need to expand access to drugs for the prevention of mother-to-child transmission of AIDS, access to ARV drugs, better and sustainable HIV/AIDS prevention and treatment programmes was made real through songs and music. A selection of songs utilized by the TAC are transcribed here for illustrative purposes. Theses transcriptions are accompanied by interviews and document reviews to interpret them in an HIV/AIDS context. Some of the song lyrics were composed by Lusikisiki TAC volunteers and staff and some are from TAC's Album Jikelele.

By 2003, the HIV/AIDS epidemic had reached crisis proportions and it was argued that truth-telling and good governance was long over-due. At this time the national TAC volunteer choir produced the Album Jikelele. According to Portia Ngcaba[48], the songs on Album Jikelele reflected the abandonment of the South African people by its own government and aided by the profiteering of the U.S. pharmaceutical industry (Interview, January 2009). Some of the songs spoke of

[48] Portia Ngcaba was the new TAC Eastern Cape Provincial Coordinator who replaced Phillip Mokoena

hope and personal responsibility, while others were a mockery. Fallen comrades included Simon Nkoli, Christopher Moraka, Nkosi Johnson, Queenie Qiza and many others were mourned and remembered through some songs. Some of the songs were personal attacks on President Mbeki and Health Minister Mantombazana Tshabalala-Msimang.

The Album Jikelele was produced by TAC volunteers, the backbone of the organization and its efforts to get affordable, quality drugs and treatment to PLWHAA. Social criticism was central to the album, it was intended to be an agent for change directed to specifically President Mbeki and his Health Minister, calling on them to fulfil their constitutional and moral obligation to protect the right to life and dignity of all peoples in South Africa.

The TAC adapted anti-apartheid songs to the new struggle against government neglect and corporate greed. The songs touched on all the main themes related to the disease: people are dying, medication is at hand, and the need to globalize the struggle for equitable access to treatment. The following songs from Album Jikelele portray these key messages.

*We don't care if they do not want to give us AZT because we will shrug off HIV*

The effectiveness of the one-line song *We Don't Care* was achieved by the text alone, but rather by its repetition. It formed a mantra of sorts. Other songs having a similar effect included the TAC Lusikisiki composition *uTAC akahluleki emzabalazweni* which translates to 'TAC doesn't get defeated in the struggle' and *uTAC akalelanga, uguqe ngamadolo* meaning 'TAC is not sleeping but just kneeling on its knees.' These one-line songs were usually repeated in different harmonies.

The three songs below were consoling to HIV/AIDS patients while at the same time addressing an important issue of the day. The songs suggested that the government did not care about them, but that the TAC did.

*Never Give Up Comrades! Hold on!*
*Those who divide us do not enter into TAC*
*Change Comrades, Change your step*

*Be consoled Nation,*
*Don't cry our TAC is going to conquer for us.*
*Be consoled Nation,*
*Don't cry, our TAC is going to conquer for us.*
*Be consoled Nation,*
*Don't cry, our TAC is going to conquer for us.*
*In HIV/AIDS, our TAC will conquer for us*

The lyrics from the above songs, while carrying consoling messages, also directly addressed the South Africa government's stance on HIV/AIDS. The same message was also reflected in the songs *Siyafa* (We are dying) and *Iyasigqiba* (Its killing us) from the Jikelele Album. The song *Iyasigqiba* (Its killing us) goes further by demanding HIV drugs be supplied by Bristol-Myers Squibbs (BMS), a U.S. pharmaceutical company that also produced Amphotericin B, a drug used to treat cryptococcal meningitis. In 2005, following pressure exerted by various organisations, BMS dropped the price of this medicine but later failed to supply sufficient quantities of the medicine to meet demand.[49]

*Whoo hu hu hu whoo hu hu hu*
*We are dying, dying, dying, dying, dying with HIV*

*It's killing us......HIV*
*HIV is killing us*
*BMS we want D4T*
*BMS we want DT1*
*HIV is killing us*

Songs become a medium and tool through which a people bonded together against common enemies, the South African government and the pharmaceutical

[49] www.tac.org.za

industry. In Lusikisiki, similar type of songs were composed and sung. Through the medium of music and song, the TAC was portrayed as an alternative to the government and a messiah symbol. One Lusikisiki community member noted, the TAC was instrumental in making things happen,

> ... TAC educates us on HIV/AIDS and other diseases like TB and STIs. It also does campaigns on PMTCT for formula milk... It also helps those who are abused of their rights and those who are raped... TAC helps us to get food parcels and grants from the Department of Social Welfare. Whatever we want, TAC is there for us (Anonymous community member).

The TAC's presence in the villages in and around Lusikisiki was easily recognizable by the songs, chants and jingles which were its trademark coupled with the purple 'HIV-Positive' emblazoned tee-shirts they wore.

*Have a look, Pfizer is making fun of us*
*Have a look, Mbeki is making fun of us*
*We are going to give them a minute to change their ways*
*Have a look, Manto has contempt for us*
*We are going to give her a minute to change her ways*

*TAC is asking when the prices will go down*
*Tshabalala doesn't want to join TAC*
*Helele Ma, Tshabalala doesn't want to*
*Thabo Mbeki doesn't want to*
*Pfizer doesn't want to join TAC*

Some, if not most of the songs composed by the TAC go to an extreme level of mockery, making fun of the targeted individuals. The songs contain a level of militancy which is accompanied by personal and institutional confrontational themes. The two songs above from Album Jikelele, *Bonanje* (Have a Look) and *Uyabuza uTAC* (TAC is asking) express the anger and frustration that was directed at Thabo Mbeki and Manto Tshabala-Msimang, and in some cases the pharmaceutical industry.

| | |
|---|---|
| *TAC wami moibambe ngesandla* | *TAC holds my hand so* |
| *Ndingatshi yiWhisky* | *that I don't get burnt from Whisky* |
| *Isibindi sikaManto siphelile* | *Manto's liver is destroyed* |

*Sesizomngcwaba uManto* *we are going to bury Manto*

Tshabalala-Msimang had paid the price more than anyone else. In another TAC Lusikisiki composed song she was labelled an outcast and seen as a destroyer. The attack on the health minister had become so politicisation that she was being blamed for many HIV/AIDS-related deaths.

| | |
|---|---|
| *Lisidlisa ngengculazi eli vezandlebe* | *She is destroying us with HIV this outcast From?* |
| *Lelakwa? LelakwaManto elivezandlebe* | *From Manto this outcast* |

It was interesting that when Finance Minister Trevor Manuel questioned the efficacy and side effects of AZT he was not called to task by the TAC. It was clear that Mbeki and Tshabalala were the targets of the TAC's anti-government campaign.

> "Anti-retroviral drugs did not "in any way" limit the spread of HIV and Aids, and could instead cause a number of diseases. Aids debate in South Africa was misplaced because it focused on anti-retroviral rather than education. 'What anti-retrovirals don't do is to change the status of somebody. Nor do anti-retrovirals on their own change the conduct of an individual who may be exceedingly promiscuous. It does not in any way limit the spread, but all of the focus is on anti-retrovirals, whereas in fact we need an educated population'...'The little I know about anti-retrovirals is that unless you maintain a very strict regime ... unless you have the facilities to deal with all of that ... they can pump you full of anti-retrovirals.' Sadly all you're going to do, because you are erratic, is to develop a series of drug resistant disease inside your body."

The South African Deputy President, Phumzile Mlambo-Ngcuka, gave new leadership to the state's response to the HIV/AIDS epidemic. With the support and blessing of the cabinet, Ms. Mlambo-Ngcuka met with the TAC to review and consolidate the membership of the South African National AIDS Council (SANAC). She agreed to address the Civil Society Congress on HIV/AIDS, and according to Philip Mokena, it was the first time that the second in command of the South African government addressed a meeting co-hosted by the TAC (Interview, 2007). At the same Congress, the then-Minister of Health, Nozizwe

Madlalala-Routledge, acknowledged the deficiencies in governmental leadership surrounding the AIDS crisis. Ms. Madlalala-Routledge expressed support for improvements in HIV/AIDS care and treatment programmes and went on to address the problems in the poorly implemented mother-to-child prevention programme, the reasons the programme had faltered, and the escalating human resources crisis in the health department. After being honoured by the TAC through songs, chants and slogans, she made an unannounced visit to Frere Hospital in the Eastern Cape. Ms. Madlalala-Routledge was appointed in a cabinet level position and the reasons for her departure from the cabinet remained unknown. In any case, soon after her marching orders, the TAC showed their unwavering support for the sacked deputy minister.[50]

**'CABINET'S HIV FIGHTER':** The photograph of the axed deputy minister of health, Ms Madlala-Routledge is printed on the TAC's purple emblazoned **HIV-POSTIVE T-shirt**. The AIDS Activist organisation, showed its unwavering support for the sacked deputy minister not only by printing her image on their trademark purple **HIV-POSITIVE** emblazoned T-shirt, but by also raising some funds for her.

President Mbeki received a barrage of criticism after his firing of Deputy Health Minister Nozizwe Madlala-Routledge, the TAC took the lead in questioning the president's motive for her dismissal. It went on to establish a fund to provide

[50] See press articles: Piet Van Niekerk, "*Sacking of Cabinet's HIV fighter 'an insult'*" and Sapa, "*TAC launches funds for axed minister.*"

short-term financial assistance to Ms. Nozizwe Madlala-Routledge[51] and issued the following statement,

> "In defence of good governance and to support Ms. Nozizwe Madlala-Routledge, a fund has been set up to assist her with short term financial needs related to non-payment of her salary and to cover any legal costs of defending these claims by the government."

When Ms. Madlala-Routledge was fired by President Thabo Mbeki, the TAC was quick to link the firing with her stance on HIV/AIDS. Furthermore, her firing was seen by the TAC as a dreadful error of judgment and an indication that the president remained opposed to the science of HIV and was unwilling to appropriately respond to the epidemic. It was also interpreted to be a "turf war" between Ms. Tshabalala-Msimang and Ms. Madlala-Routledge.

The TAC's motives in the battle for HIV/AIDS medication in many instances could be questioned. Some believed that President Mbeki's suspicions about the AIDS industry comprising multinational corporations, United Nations, foreign NGOs, academics, and drug companies were justifiable, particularly given the profits involved. The fight for access to HIV/AIDS medications and evidence-based policies and programmes had become personalised in spite of President Mbeki's acknowledgement that HIV causes AIDS (Roberts, 2007). From interviews and fieldwork conducted for this thesis, a lot of TAC sympathisers, members, and volunteers and other members of the Lusikisiki community believed that President Mbeki and Health Minister Tshabalala-Msimang were against the roll-out of ARV drugs and that they did not acknowledge the connection between HIV and AIDS.

> *We know AZT globally*
> *AZT – we know it*
> *It is protecting children from HIV globally, globally MTCT prevention*
> *We know Nevirapine*
> *It is protecting children from HIV globally, globally*

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[51] While the "Support Good Governance – Support Nozizwe Madlala-Routledge Fund" was managed and accounted for by the AIDS Law Project, the committee however included Andrew Feinstein (former ANC MP); Adila Hassim (Acting director of AIDS Law Project); Vuyikazi Matiso (TAC national executive member) and Cheryl Gilwald (former deputy minister of correctional services).

Roberts (2007) argues that the TAC's mobilization focus on access to AZT and Nevirapine had turned it into a group of drug-fundamentalists.

*Emazweni bakhala ngathi*
*They cry about us in the country*
*They cry about 3TC*, *They cry about D4T*
*They cry about AZT*
*They cry about Triomune*
*Bhakala ngeDT1 (they cry about DT1)*

*Nevarapine siyayazi ikhusela abatwana* (*We know Nevarapine protects children)*
*Kwi HIV jikelele From HIV all around*
*MTCT, MTCT, MTCT, MTCT*, *MTCT, MTCT, MTCT, MTCT*

The cries and shouts for medication were heard through Lusikisiki TAC members songs such as *Emazweni bakhala ngathi* (They cry about us in the country) and *Nevarapine siyayazi ikhusela abatwana* (We know Nevarapine protects children).

In a memorandum TAC presented at a Global Fund conference in Durban, it demanded $2 billion in drug spending while no funds were requested for food (Roberts, 2007). This was worrisome as the prioritisation of funding for drugs was also an issue in Lusikisiki. Patients on ARV therapy were beginning to complain about the lack of food, they could not take their medications on empty stomachs.

This chapter has focused on the cultural/political dimensions of MSF and the TAC in Lusikisiki in the mid-2000s. Two arguments have been presented. The first focuses on the charismatic Dr Reuter and the reception he received in Lusikisiki. Based on my own observations from spending time with him and observing the ways in which he was represented among community members, his visits to community gatherings, and the stories that circulated about the medicines he brought to heal the sick, he was seen as a messiah by many of the local residents. Dr. Reuter was viewed as a prophetic figure among the many that preceded him, which allowed him to have a significant and positive impact on the health and well-being of the residents of Pondoland. This perspective

provides some insight into how he was received and why local people with a long resistance to white intervention accepted his message of hope with such enthusiasm. A pre-existing cultural script existed in the region which helped to shape his reception and that of the HIV/AIDS programme in Lusikisiki.

The second part of the argument concerns the anti-Tshabalala-Msimang activity in the region. The vilification of the Minister was what Monica Wilson referred to as “the collective nightmare of the group.” This focus on the person of Minister Tshabalala-Msimang was not unique to Pondoland but rather abounded in the South African media and the international community. The attack on the South African governments HIV/AIDS policy was on one hand very personalised and in that sense connected with local idioms of victimisation and witchcraft, but on the other, it personified the rural struggle which was embedded in a wider cultural and political frame.

The portability of songs, slogans, prayers, and *toyi-toyi* has historically allowed these modes of expression to play a crucial role in unifying oppressed communities and serve as a reminder to the South African government of the need for action. In the case of the struggle against apartheid, Ntuli notes,

> At the height of the South African madness ... Others were engaging apartheid with guns. Others were engaging them through discussion. Others through prayer. Others were engaging them through songs. That’s how we managed to turn the tide of the world (Sifiso Ntuli, 2003).

## Chapter 9: Food and Drugs: Rural Politics and the Ambiguities of Dependence

A social movement's power to influence behaviour and opinion is dependent on the movement's ability to generate historical and other symbols that people can easily and quickly identify with (Midgal, 2001). The TAC successfully utilized these symbols to identify with people through the historic memories attached to the symbols. The TAC used revolutionary and liberation songs, slogans and *toyi-toyi* as a strategy to mobilise the residents of Lusikisiki in the fight against HIV/AIDS. One TAC volunteer had this to say,

> HIV is a big problem in Lusikisiki. People are dying here. Some come from Durban and Cape Town to die here, but some get sick here and die here. Some people join TAC and easily get help, while others just die. TAC and MSF are helping us to get ARV drugs and sometimes the grant to buy food. We support TAC and MSF because they help us a lot. We sing with TAC to the department to get help... We know the department does not care. TAC and MSF care for us...

The TAC became a legitimizing institution in Lusikisiki. To a large extent, TAC volunteers and other community members supported the work of MSF and organizing and educational efforts of the TAC. What I observed during public hearings organized by TAC was that it was primarily TAC volunteers who raised questions and expressed their dissatisfaction with local government. Community members attended TAC gatherings and in return receive Kentucky Fried Chicken's Streetwise Two and a juice after which they usually departed.

The TAC in Lusikisiki filled a notable gap in the politics of rural mobilization. Political mobilization in rural areas like Lusikisiki had last taken place on a large scale in the late 1950s when peasants mobilized around the Bantu Authority laws and agricultural betterment and rehabilitation policies. Popular peasant resistance to cattle culling and state interference with the election of chiefs and headman became widespread by 1960. Rebels in the district set up a semi-

clandestine movement called Intaba (mountain top), its members were men who moved around on horseback and met on hill tops in the Bizana, Flagstaff, and Lusikisiki districts to strategise, plan, and issue verbal directives. By the mid-1960s, Intaba had become so powerful that it usurped the functions of government-appointed chiefs and was conducting people courts and adjudicating the allocation of land. Chiefs were so intimidated by the Intaba and its followers that many resigned. Those who opposed the movement had their kraal and homes burnt to the ground. In November 1960, the state eventually intervened to bring the revolt under control. They sent troops into the area and attacked crowds from the air with planes and helicopters. In the investigations that have been undertaken into the Mpondo revolt it has been alleged that outside organisation like the African National Congress (ANC) or the Pan African Congress (PAC) or white communists were orchestrating events, but there has been little evidence to support this view. It is generally understood that the Mpondo revolt was a peasant uprising which was led and organized from the ground. The state crushed the movement through the use of security forces and their leaders were arrested (cf. Mbeki 1962; Karis and Gerhard 2013).

Although the Pondo uprising of 1960 and the rise of the TAC in Pondoland in the 2000s dealt with different socioeconomic issues, it is interesting to note how the lead organization in both cases captured the imagination of the rural poor. In the 1960s, the mounted horsemen of Intaba roamed the countryside, they were viewed as Robin Hood figures fighting for the rights of ordinary people in the face of state repression. Likewise, the locals in Lusikisiki saw the TAC as capable of delivering damaging political blows to an unresponsive state and its allies. The resources that TAC was instrumental in securing from international donors channelled through the MSF demonstrated that it had the means to deliver drugs to the community. Continued international donor support was contingent on MSF and TAC fully engaging the community in their efforts.

The mobilization tactics of the TAC were often oppositional and confrontational and it was this spirit that they brought to meetings and public events. There was considerable unease among some at the local level that aligning with the TAC might alienate local governmental officials. These local people understood that access to resources rested on patronage linkages, on a politics of deference and dependence, where the poor acknowledged the power of local elites. For these reasons, it was felt that being too closely aligned with the TAC could be counter-productive.

From the perspective of the rural poor residents of Lusikisiki, the survival of the HIV infected depended on access to both food and drugs rather than one or the other. It is for this reason that the poor increasingly pushed for the politics of compromise in the hope that they might become benefactors of both the AZT and related health services, and the state for subsistence grants to buy food. This chapter explores these competing needs and demonstrates how the poor eventually lost both drugs and food by virtue of the politics of compromise.

**9.1 The Lions of Lusikisiki**

The TAC, as a rights-based HIV/AIDS social movement organization, has been viewed by some as a feared lion and bully in Lusikisiki. As the most famous NGO in Lusikisiki, this viewpoint is supported by the TAC song *uTAC yingwe* (TAC is a lion) which has the same lyrics and melody as that which was chanted when the late Dr. Hastings Kamuzu Banda's came into power.[52]

| | |
|---|---|
| *uTAC yingwe* | *TAC is a lion* |
| *Uyingwe safumana itreatment* | *We got treatment because you are a lion* |
| *Satsho saphila* | *We finally got cured* |

The TAC fought vociferously and untiring for universal access to affordable ARV drugs, so much so that its founder, Zackie Achmat, a former anti-apartheid

[52] Dr. Hastings Kamuzu Banda is the first and former president and dictator of Malawi

turned AIDS activist, once stopped taking his medication in protest to put pressure on the government for universal access to ARV drugs (Roberts, 2007). He eventually resumed take his ARV medications after a heart attack in 2004, when it became clear that he would quickly die without treatment (Roberts, 2007).

At the same time, in 2004, the federal government capitulated to the demand that ARV medications should become available on a nationwide basis, and started their dispersal in public hospitals in March 2004. The TAC continued to agitate, periodically suing the government through the AIDS Law Project to accelerate the rollout. The TAC won court cases against both the pharmaceutical industry and the South African government.

| | |
|---|---|
| *UTAC akahluleki emzabalazweni* | *TAC doesn't get defeated in the struggle* |
| *Ndino TAC, ndinengangalala* | *I have TAC, I have a pillar* |
| *Ndino MSF oligorha* | *I have MSF who is my hero* |
| *Wena TAC, nawe MSF* | *You TAC and MSF* (TAC Lusikisiki) |
| | |
| *Ndino TAC ndinengangalala* | *I have TAC, I have the pillar* |
| *Ndino MSF oligorha* | *I have MSF who is a hero* |
| *Wena TAC, nawe MSF* | *You TAC and MSF* |
| *Ndiyazi mna* | *I know* |
| *Ngeke nihlekise ngam* | *That you will never make fun of me* |
| *Nob'iHIV seyindihlasela* | *Even when HIV is attacking me* |
| *Nob'iAIDS indidlazula* | *Even when AIDS is destroying me* |
| *Ii ARV drugs zizolwa nayo* | *ARV drugs will fight with it* |
| *Ndiphile mna bon'ubom'obude* | *And I will live for a long time* |
| | *And I will live a longer life* |
| | *And I will live for a longer period of time* |

The TAC enjoyed unqualified support from Lusikisiki residents for the many activities in which it engaged, this was despite the view of some governmental officials that the TAC was a drug-fundamentalist organization.[53] Mobilization around increasing access to HIV/AIDS drugs in Lusikisiki was just one of many activities that earned the community's support, loyalty, and bestowing the title of

[53] For more discussions on drug fundamentalism I refer you to Ronald Suresh Roberts, *Fit to Govern: The Native Intelligence of Thabo Mbeki*. (Johannesburg: STE Publishers, 2007).

"lion, pillar and hero." The TAC has become a force that the local governmental agencies had to deal with. Besides holding the Eastern Cape DOH and other government units accountable with *toyi-toyi*, they also went to the media to make their case. Bavuyise Vimbani[54] noted that the TAC

> …now acts as a pressure group on almost anything in Lusikisiki. On the HIV/AIDS and health service front, we (HAACO) uses TAC to put pressure on the Department of Health when there are problems in hospitals and clinics that we work in. For example, the shortage of doctors, nurses and drivers; sometimes the shortage of formula milk...HAACO uses TAC to scare and confront the Department of Health each time we see these problems. Once TAC is alerted, it acts and confronts the Department of Health or any relevant government department. It uses threats where necessary... (Interview with Bavuyise Vimbani, 22 November 2007).

When I asked Noloyiso Ntamehlo, Lusikisiki' s TAC District Co-ordinator about how they solved problems and met the challenges they faced in Lusikisiki, she had this to say,

> "When faced with problems and challenges with the DOH or any other government department for that matter, we threaten them with public campaigns, *toyi-toyi* and going to the media. MSF used to come to some with problems that they were facing with the DOH and today HAACO does the same thing and our job is to threaten the Department of Health. We do the same thing if there are problems with other government departments, even with the police" (Interview, 21 November 2007).

While HIV/AIDS information, education, and activism remained on top of the TAC agenda in Lusikisiki, it became increasingly difficult to ignore social problems that were contributing to the high rates of infection in Lusikisiki such as rape, gender violence, social grants, and other socioeconomic issues.

### 9.2 The Agency of *Toyi-Toyi*

*Toyi-toyi* is a Southern African dance originating from Zimbabwe that became famous for its use in political protests in the apartheid-era in South Africa. *Toyi-*

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[54] Bavuyise Vimbani was a former MSF Adherence Counsellor who was later appointed the HAACO Project Administrator

*toyi* often begins with the stomping of the feet and spontaneous chanting. During protests, the stomping and chanting can include political slogans or songs, either improvised or previously created. . Since the end of apartheid, South Africans have used *toyi-toyi* to express their grievances against government policies, HIV/AIDS policies and programmes grievances were not immune to *toyi-toyi*.

After the 1976 Soweto massacre, the liberation movement became more militant and songs were charged with imagery of armed struggles for liberation. The *toyi-toy* became commonplace in demonstrations. As one activist puts it, “The *toyi-toyi* was our weapon. We did not have the technology of warfare, the tear gas and tanks, but we had this weapon.”

**TIME FOR REAL CHANGE...:** Treatment Action Campaign chairperson and founder Zackie Achmat, third from left, is flanked by TAC members on his right and members of the South African Communist Party and Congress of South African Trade Union on his left in Queenstown.

Below are some of the slogans chanted by the TAC during its protests at public hearings, accreditation of ARV sites, and for protesting against the government’s inaction.

| | |
|---|---|
| *Amandla, Amandla!!!!* | *Power, Power!!!* |
| *Awethu!!!!!!* | *Is ours!!!!!!* |

*Viva TAC Viva!!!!*
*Viva the spirit of no compromise Viva!!!*
*Long live the spirit of no compromise!!!*
*Long live the spirit of Chris Hani, long live!!!*
*Long live the spirit of Robert Sobukwe, long live!!!*

*Viva the spirit of asijiki Viva!!!*
*Viva the spirit of no turning back Viva!!!*

The mention of late ANC stalwarts and other respected liberation leaders suggested that the TAC wanted to be associated with the ANC and the poor. Slogans became an effective tool used by the TAC in its confrontations with the government and efforts to push for the revamping of HIV/AIDS policies and programmes.

The TAC‘s involvement in the Lusikisiki HIV/AIDS Programme was a calculated move by MSF. Bringing in the TAC added the pressure on the local government that MSF needed to be an effective prevention and treatment programme. The TAC served as a catalyst, putting pressure on the Eastern Cape Department of Health and on other government agencies through *toyi-toyi* and other confrontational tactics. According to Jouquet, *toyi-toyi* was an effective way to make the government act more quickly (Interviews with Reuter and Jouquet, August 2006).

HAACO staff member Vimbani concurred,

> TAC acts as a pressure group, pushing the DOH to respond to problems. For example, TAC will always make noise about the shortage of nurses, drivers, formula milk and the unavailability of doctors among many other issues. It also threatens the DOH with going to the media and do *toyi-toy*i if it (DOH) fails to deliver or act on anything. When we take issues to TAC, they confront the DOH through *toyi-toyi*... This is TAC’s job, they have been doing this for MSF too... MSF will give TAC information and TAC will just act on it... We (HAACO) use TAC to confront the DOH when there are crisis and dire problems. HAACO has the first-hand knowledge of what is happening in clinics and hospitals. We are aware of the problems and issues which the DOH is always grappling with. The moment we see the DOH reluctant to act, or any other relevant department for that matter, we ask TAC to confront the department. Once we take the issue to TAC, it confronts the relevant department with all sorts of threats, including going threatening to the media and *toyi-toyi* (Interview, November 2007).

MSF and HAACO never publicly took part in the *toyi-toyi* against the DOH's inaction as they did not want to jeopardise they relationships with the DOH, although both organisations supported the TAC's activism and *toyi-toyi*. The national and regional publicity about the Lusikisiki HIV/AIDS Programme explains, in part, the reception of TAC's activism and *toyi-toyi* by the DOH and other local governmental agencies. Because the programme had become a model in South Africa, the DOH tried to contain the TAC's influence by withholding important information and making it difficult for them to gain access to hospitals and clinics.

> We [MSF] would give TAC information that the DOH would have otherwise withheld from them and this helped them to confront the department... We used TAC to challenge the department and to keep them awake... Our relationship with TAC was very crucial (Interview with Dr. Reuter, August 2006).

According to Mokoena[55], it was difficult for the TAC to get HIV/AIDS statistics from the DOH (Interview, September 2006). Once the TAC obtained suspicious data they often went to the media with the information.

Some clinic and hospital nursing staff that I spoke with on the condition of anonymity indicated that it was through *toyi-toyi* that the TAC continued to have a significant impact in Lusikisiki, not only on HIV/AIDS-related issues, but also on improving the quality and responsiveness of health services delivery.

### 9.3 The Politics of Engagement and Social Grants

Before its departure, MSF realized it needed to engage in strategies that would strengthen the relationship of the clinic with the Eastern Cape DOH since it were taking over the sponsorship of the clinic. To do this, MSF supported the establishment of a new local NGO, one that understood the political dynamics of the relationship between the TAC, MSF and the DOH. Recognizing the critical importance of the role that adherence counsellors played in the programme, MSF included in its exit strategy the establishment of HAACO. The role of HAACO

[55] Phillip Mokoena was the first Eastern Cape TAC Provincial Coordinator

was to ensure that activities, engagements, and relative roles of the tripartite alliance would continue once MSF left the programme. Key to these activities was the public hearing process as it was the vehicle to bring the various community stakeholders together to provide continuous accountability for HIV/AIDS service delivery in Lusikisiki.

The HIV/AIDS Adherence Counsellors Organisation (HAACO) was designed to, among service delivery responsibilities, attract external funds (with the assistance of MSF) to sustain the programme created by MSF upon its departure. HAACO employed all 19 adherence counsellors that were already deployed by MSF to all the clinics and the hospitals around Lusikisiki, Flagstaff and Bizana. HAACO, like its soon-to-be predecessor MSF, had to sign a memorandum of understanding with the Eastern Cape Department of Health (ECDOH). HAACO was expected to advocate and lobby for the clinics and hospitals within the Eastern Cape region. HAACO would be responsible for facilitating the ongoing politics of engagement as well as filling in the gap left by MSF.

One of the urgent issues that HAACO had to deal with was patients' adherence to the ARV therapeutic regimen and the continuance of HIV/AIDS disability grants. Many HIV/AIDS infected individuals were discontinuing their medications in order to maintain and/or re-qualify for their disability grant. The issue is that once the drugs have achieved their optimum effectiveness the individual is no longer "disabled," therefore, discontinuing therapy became a common strategy. Patients stopped taking their ARV drugs in order to qualify for the grant and alleviate their financial problems. This issue was at the centre of agenda during a November 2007 public hearing.

### 9.4 The Politics of Public hearings

On the 22nd of November 2007 I attended a public hearing in Lusikisiki which was organised by the TAC. The purpose of the hearing was to bring community

stakeholders together to discuss service delivery issues with a particular focus on HIV/AIDS. The TAC had sent formal invitations to individuals from various provincial government departments and mobilised the community through established structures to ensure community participation. It also used local organisations and NGOs to spread the message that the hearing was taking place. The organisation was a major event for the TAC, taking several months to organize. One of the reasons why so much care was taken in organising the event was that TAC wanted a hearing of this type to be held on an annual basis.

The event was organised in an open public space at the centre of the town where tents were erected and temporary facilities were provided. MSF provided the funding for all the equipment, entertainment, food, and transportation. The event began in the morning with various local religious and cultural groups providing entertainment while community members assembled. Once the tents were starting to fill, local HIV-positive TAC members took to the stage to tell their personal stories and to encourage others in the audience to get HIV-tested for become TAC volunteers. In the tent there were pamphlets, free condoms, and tee-shirts which were given out for free to community members. TAC members were available to explain where locals could get tested and join the organisation.

As I waited for the public hearing to begin with a gathering of HIV/AIDS stakeholders from Lusikisiki comprising NGOs, CBOs, FBOs, governmental officials, and the South African Police Services (SAPS), songs of liberation and chanting of HIV/AIDS, ARV, Nevirapine and PMTCT slogans were in abundance. Songs included personal attacks on Minister of Health Tshabalala-Msimang and President Mbeki. A passer by or newcomer to Lusikisiki could have mistaken this public hearing for a political rally.

After a couple of hours the main speakers were introduced, included TAC provincial leaders and Dr. Reuter who welcomed the assembled and introduced the day’s agenda. He explained that the function of the meeting was to create an

on-going dialogue between community stakeholders and residents to ensure that there a multi-pronged approach to the challenges of the HIV/AIDS epidemic in the broader Lusikisiki community. The public hearing process would create a space and venue for dialogue. Events like this November 2007 public hearing became increasingly common in Lusikisiki as the TAC sought to increase the engagement of provincial governmental agencies in the campaign to fight HIV/AIDS.

For the initial period of opposition in the early 2000s, TAC had increasingly moved to incorporate government officials and agencies in its strategies. In Lusikisiki, the formation of HAACO was a critical component of TAC's strategy to increase governmental involvement to ensure the sustainability of HIV/AIDS programmes.

According to Noloyiso Ntamehlo[56], Dr. Herman Reuter was to be credited with the idea of using the public hearing process to fully engage community stakeholders in a range of community health issues (Interview, 21 November 2008). Dr. Reuter believed that during a public hearing, community stakeholders would have the opportunity to engage in a dialogue and subsequently be held accountable (Interview with Dr. Reuter, August 2006). "No stone [will be] left unturned during this three-day public hearing session" (Interview with Nosizwe Mjoji). Dr. Reuter noted that a particular focus would be on government agencies, "are all these sectors and institutions doing their job, are they meeting community needs? Are they serving the community as they promised?" (Interview with Reuter, August 2006).

While the hearing was Dr. Reuter's initiative, it was coordinated and facilitated by the TAC with all members and volunteers from its branches surrounding Lusikisiki attending. Lunch, dinner, and accommodations were organised for

[56] Noloyiso Ntamehlo was the TAC Lusikisiki member and District Coordinator

more than 500 TAC members and volunteers who were expected to attend. From my observation, it was more a TAC than a community-wide event.

What I also observed was that the local NGOs and other community members present were there to support the TAC who were largely former TAC members and volunteers. For example in an interview with Bavuyise Vimbani, the Project leader of HAACO, he stated,

> I was busy for the last two days with another HIV/AIDS awareness event with the Department of Health. HACCO, the TAC, and the department [Eastern Cape Department of Health] co-hosted workshops and events together. We support each other as local NGOs in many events. Tomorrow I will therefore be attending the public hearing. TAC needs our support (Interview with Vimbani, 21 November 2007).

Other civil society organizations that I interviewed also spoke of the need to support the TAC-organized event.

### 9.5 HIV/AIDS Social Grants

South African governmental policy stipulates that HIV-positive disability grant recipients are to be deregistered once antiretroviral (ARV) treatment restores them to good health and they are able to start seeking employment. However, local AIDS activists charged that with national unemployment estimated at around 35 percent, most beneficiaries who were jobless and too sick to work or seek employment before they started receiving the monthly stipend of US$109, would not suddenly become employable because their CD4 count levels had increased to a normal range.

People who are sick with AIDS or with HIV-related opportunistic infections may be unable to look for and/or to take up an employment offer. The stated purpose of the disability grant for HIV-infected persons was to provide support for nutritional needs until they were restored to health and able to re-enter the labour force.

Different provinces in South Africa use different criteria for assessing disability, with most of them relying on evaluations by medical officers or district surgeons, while others relying on an '*assessment panel*'. The Western and Eastern Cape Provinces for example, opted not to introduce assessment panels but to use medical officers to assess disability. A general rule that applies in most hospitals and clinics throughout the country is that an individual with a CD4 count of ≤ 200, which is roughly associated with clinical stage 4 AIDS, meets the clinical criteria for receiving a disability (HIV/AIDS) grant (Simchowitz, 2004,

Prior to the roll-out of ARV drugs in 2004, many people living with HIV/AIDS (PLWHAs) received disability grants when they became sick from AIDS and unable to work and/ or seek employment. With access to ARV drugs, and therefore renewed health, many PLWHAs stand to lose the grants as a result of their improved health. This is particularly problematic in South Africa with its high levels of unemployment and poverty (HSRC, 2009; Seekings and Nattrass, 2005).

The roll-out of universal access to ARV drugs in 2004 changed the many challenges faced by HIV-positive individuals in South Africa. Prior to 2004, many PLWHAs accessed disability grants when they became sick with AIDS-related opportunistic infections. The loss of this disability grant had a substantial impact on AIDS-infected individual's socio-economic status and health.

As the number of people losing their disability grants was projected to rise to about half a million by 2010, it was important to assess the consequences of grant loss and the measures taken to prevent or mitigate this shock. This potential trade-off could have serious social implications and may contribute to the development of resistance to ARV drugs.

Given that some of the PLWHAs could no longer access disability grants, the finances of their entire households as well as their extended families were

adversely affected. Loss of the disability grant also had social implications. The disability grant gave PLWHA positive standing in their families. When the disability grant was terminated, the motivations for disclosure to the family were undermined.

Owing to the low income status of families of PLWHAs, disability grants were regarded as a source of income for the basic expenses of people in need of care. Many HIV-infected persons described experiencing stigma from their family members who provided care.

Doctors are principally responsible for recommending whether or not PLWHAs are eligible for disability grants and for stipulating the duration of each grant award. As stated before, there are no clear national guidelines the determination of eligibility for these grants which gives doctors some flexibility in the disability determination process. Some doctors I interviewed who asked to remain anonymous acknowledged that, in addition to health criteria such as CD4 counts, they also used social criteria when deciding who qualified for disability grants. As such, doctors reported feeling uncomfortable and pressured to recommend disability grants for PLWHAs. At the same time that expectations surrounding the disability grant determination process was referred to as the most important challenge facing the doctors' daily work.

**9.6 Starving on ARV drugs**

In her book, *Starving on a Full Stomach,* Diane Wiley (2001) explored the cultural dimensions of the politics of hunger and malnutrition in South Africa. The book scrutinises the formation of complex ideas about hunger and deprivation in South African rural areas, paying special attention to Pondoland in the former Transkei. Wiley argues that the definitions of hunger and malnutrition have changed over time as social and medical scientists have reflected on the African condition. The development of nutritional science in the early 20$^{th}$ century led Europeans to frame questions of hunger in terms of diet alone rather than in the socioeconomic

context of wages and social grants. Using European cultural standards and practices, intellectuals and officials in South Africa in the 1920s and 1930s started to argue that African malnutrition was the fault of poor Africans because they did not select the correct diet. Local people were to blame for their hunger rather than a system that paid starvation wages and alienated people from their land. This disconnect was termed the medicalization of hunger. Wiley discusses how in Pondoland during the first half of the 20th century, social reformers, government officials, and labour recruiters debated issues of hunger and deprivation in Africa. She argues that to judge African dietary practices by European standards and then blame Africans for their poverty and malnutrition, as if this had been a pre-colonial condition, amounted to cultural racism. Her textured and detailed study provides valuable insight into the food and drugs debate in South Africa during the 2000s (Wiley 2001).

By focusing on prevention, education and ARV treatment in the fight against AIDS at the local level, TAC placed less emphasis on the socio-economic impacts of the disease, namely that its biggest impact was on the poorest of the poor. Alternatively, President Mbeki took as his primary position that HIV/AIDS was a disease driven by poverty and that it would not be eradicated without interventions that recognised the link between poverty and HIV/AIDS.

As the debate between the TAC and other social reformers and Mbeki's Health Minister grew ever more vitriolic, the conflicting images of the TAC as a drug fundamentalist organization and Ms. Tshabalala-Msimang as a champion of the African sweet potato, beetroot, and garlic, sharpened the edges of the policy divide between drugs and diet. From the perspective of the rural poor, issues inadequate dietary intake were inextricably linked to poverty, social grants and lack of employment opportunities.

While the TAC continued to advocate for HIV/AIDS information and prevention programmes and universal access to ARV therapy, others on the ground took the

politics of engagement activities as an opportunity to put pressure on the state for increasing access to adequate social grants.

Community members present at the November public hearing were invited to air their grievances and ask questions directly to governmental officials at the hearing. Of all the questions and grievances that I recorded, the majority of grievances were directed to the Departments of Health and Social Development and to the South African Social Security Agency (SASSA). The hue and cry was about food, food parcels, and disability grants as opposed to access to ARV therapy-related issues. Holding out her empty medication container, one of the TAC volunteers lamented,

> I finished my ARV drugs yesterday and I was told to come back tomorrow by sister in-charge. Why? Where are the ARV drugs, in Mthatha? If I get my ARV drugs I am taking them on an empty stomach. I also need my HIV/AIDS grant to buy food... I am hungry. When my CD4 has risen above 200 I stop getting the grant. Why? The grant should continue!!! (Anonymous TAC Volunteer).

Below is a picture of a TAC volunteer at the hearing.

**ARV drugs ARE TOXIC....WE NEED FOOD.** Looking on as a TAC member makes her point is the TAC Lusikisiki District Organiser, Noloyiso Ntamehlo, and TAC Lusikisiki Administrator, Nombeko Gqamane, one of the scribes at the November public hearing.

## 9.7 Why HIV/AIDS disability grants are an issue

During the public hearing, I conducted interviews with HIV-positive individuals and doctors and this is what they had to say.

### *9.7. 1 Interview # 1*

*"At the moment I am fine. I can go to work. Our government must give us more tablets… We [PLWHAs] must get stronger. Our government must accept us [PLWHAs] as normal people. We are infected by this disease – all people must accept us! We are not dead already or dying. The government must accept us and give us jobs; they must treat us like anyone else [a person that is not HIV infected]. They must not think that an HIV-infected person is going to die tomorrow. They must give us opportunities like somebody! The government must not wait for somebody to die. It must also not wait until a person's CD4 count is less than 200, because that person cannot do anything! I am sure you can understand? The government must look after and support us. I can get sick anytime, two or three times a week, but I do not want to be sick. I do want to get a job!" (*HIV+ woman aged 40*)*

### *9.7.2 Interview #2*

*"You get very sick once you lose your HIV grant, because you get depression and have no food. After that your CD4 count goes down, and you don't know what you're going to eat. People become sick all the time because they need to take medication. But, if you don't have money to buy food, it will be difficult, and you cannot get money from family because they are old and also granting. No one will help you. If you are unemployed, you will be experiencing more problems because you have to buy food, pay fees for children, buy clothes and pay for funerals with that HIV grant." (*HIV+ woman aged 27*)*

### *9.7.3 Interview #3*

*"I just tell the doctor sometimes, when I am hungry …, I don't take my ARV drugs, I just leave them [tablets] lying there somewhere … and then I'll see and wait for food to eat the following day, and then maybe take my ARV drugs." (*HIV+ woman aged 33*)*

### *9.7.4 Interview #4*

*"Nationally there are no clear guidelines. It varies from province to province, and even in this province it varies from doctor to doctor. Some doctors are hesitant to write a disability grant while others give just about anyone a disability grant. Some doctors still prescribe permanent disability grants – duration five years – while other doctors never do it. Locally, there has been some sort of agreement – if your CD4 count is less than 200 then you qualify for a grant. However, some doctors will give it to you for six months and other doctors will give you a 12 months grant." (*Anonymous doctor*)*

### *9.7.5 Interview #5*

*"I always enquire about their employment. If they are employed, and their general health condition is good, I do not offer disability grant. In cases where there is no income through employment, I offer disability grant. I have offered disability grant to all those who start ARV drugs regardless of their CD4 count. I have even prescribed ARV drugs for patients whose CD4 count is above 200. I base my assessment for initiation of ARV drugs on the general health condition of the patient, tuberculosis relapse and patients' readiness. I just about always ask for a twelve-month grant period. I do not know about any cut-off points in earnings for meeting the disability grant eligibility." (*Anonymous doctor*)*

### *9.7.6 Interview #6*

*"A lot of patients here don't take the tablets every day as required. These patients put their health at risk. General workers and cleaners at this facility always find lots of tablets dumped everywhere everyday… they find them in the yard, in the toilet…. Everywhere general workers and cleaners tell me every day that they saw someone in the bathroom who dropped tablets in the toilet. In fact, patients are heard discussing how they are manipulating the number of tablets. They count how many tablets they should be left with and they teach each other outside. They talk among themselves that if you take your tablets religiously, you*

*will get better and your CD4 count will go up and the grant will stop. So they seriously play with their health.” - (*Anonymous Doctor*)*

### *9.7.7 Interview #7*

*“The most difficult thing about being a doctor is that you have to write disability grants. It is like you are God. You just have to look at the person’s face and decide about whether they qualify or not.” - (*Anonymous doctor)

The proposition put forth in this chapter is that the tension between grants to buy food and life-saving drugs has led many PLWHA to not adhere to their ARV therapeutic regimen thus compromising the effectiveness of the therapy. This tension serves to highlight the complexities involved in intervention strategies that treat the whole person as well as an entire community. Medicine alone will not stop the spread of HIV/AIDS in rural communities like Lusikisiki, it requires a multi-pronged, cross-agency approach from the part of government and a more all-encompassing, cross-sectorial approach to community-building from NGOs, churches, and other civil society organizations.

Diane Wiley’s thesis about the relationship between cultural racism and nutritional science in Pondoland illuminates the complexity of the problem in an HIV/AIDS context in Lusikisiki. Her argument that segregationist and apartheid officials blamed the poor for their own hunger, suggesting that local diets were deficient, and that hunger was a cultural problem denies the significant influence of poverty and all that it entails.

It can be persuasively argued that the root cause of hunger in Pondoland was poverty that was linked to extremely low migrant wages and various Land Acts that discriminated against rural poor black Africans. In a similar way, the primary focus on drugs in the HIV/AIDS campaign in Pondoland has contributed to the medicalization of the HIV/AIDs epidemic.

In spite of how progressive the social mobilization tactics of the TAC were, its agenda in Pondoland was built more on a bio-medical platform and less on a socio-economic one. It was based on a basic human rights agenda as opposed

to an entitlement agenda that included entitlements to social grants and food security. This created what I term ‘ambiguities of dependence’ where the rural poor in Lusikisiki were eager to align themselves with the TAC on one hand, but could not break their ties to the local welfare state as grant recipients. As disability grant recipients, many felt pulled to choose between a cash grant and life-saving drugs.

In the next chapter we turn our attention specifically to the local media and their role in reporting on the HIV/AIDs epidemic in the Eastern Cape.

## Chapter 10: Media Bias, Local Realities: Representing the HIV/AIDS Crisis in Lusikisiki

In the previous chapter I explored the complexities of the tension between drugs and diet in Lusikisiki. I also described how the politics of engagement in the late 2000s brought the TAC and local government agencies closer together and created the space for rural people to get both drugs and social grants.

In this chapter I explore the role of the media and their editorial reporting on what was unfolding in Lusikisiki. I suggest that the media adopted the arguments and perspectives of national and international reporting on the HIV/AIDS epidemic rather than critically reporting at the local level. This chapter will reflect on some of the stories and question their validity by reflecting on contradictions between local events and how the media portrayed them.

In the past three decades, we have witnessed the influence of the media in framing the debate and circumstances surrounding the HIV/AIDS epidemic, both in South Africa and globally. This influence has been, at times, not well-informed by the latest scientific evidence available and demonstrates the considerable bias in reporting based on the political inclinations of the editorial staff of the paper involved or the ownership of the TV network. The media has become so powerful that it can sway public opinion about people, events, and political institutions. As such, the media has been rightly accused of distorted facts, invasion of individual privacy, and actively attempting to shape public opinion. As I discuss in this chapter, the media in South Africa has played an influential role in constructing a reality about the HIV/AIDS epidemic that has sensationalised the disease.

### 10.1 The Power of the Print Media

In his book, *Imagined Communities: Reflections on the Origins and Spread of Nationalism,* Benedict Anderson links printed material with cognition. Print is

associated with cognition, universalism, monolinqualism and permanent memory (Anderson, 1981). Concurring with Anderson, Peter Wogan writes,

> Print accounts for the major cognitive, transformation that engender imagined, national communities: above all, the crucial changes in conceptions of time – from messianic to simultaneous, homogenous time – are attributed to the reading of novels and newspapers. In addition, the awareness of fellow citizens is attributed to the daily consumption of newspapers.

Revealing the dichotomy between print and oral communication that underpins Anderson's *Imagined Communities*, Wogan argued that print is what allows the nation to be conceptualized, while oral language gives it emotional force; or put differently, print allows people to imagine the nation, while orality makes the people love or die for the nation.

Print media is seen by many as the voice of the community, it engages people who want to believe that the newspapers they read provide honest and comprehensive news about local and national events. Newspapers have been described as harnessing words out of mouths. Newspaper readers often will tell neighbours and friends about specific news items they have read. As a result, the media plays an important role in disseminating information and influencing public opinion (Moscovici, 1961; Gillwald, 1993; Thompson 1995 as quoted in Campbell and Gibbs, 2008).

Furthermore, the media serves as a vehicle for discussing and debating ideas, social problems, successes and challenges of governance (Parker and Kelly, 2001 as quoted in Campbell and Gibbs, 2008). Hence, in the context of media and the HIV/AIDS epidemic, the media is seen as a mediating influence that informs the public's perception of HIV/AIDS (Hodgetts and Chamberlain, 2006). This influence, whose accuracy and objectivity is at times questionable, reaches a large readership through the print media. Shisana, et al., (2005) as quoted in Campbell and Gibbs noted that,

> A nationally representative South African survey points out that while most people get information on HIV/AIDS from radio and television, about half of those aged 15 to 49 use newspapers as an important and additional source of information on HIV/AIDS, and the readers include decision-makers, health practitioners and activists (Campbell and Gibbs, 2008: 46).

### 10.2 Role of Media in Informing the Public about HIV/AIDS

Several empirical studies have shown that the media plays a significant role in either mitigating and/or contributing to the negative perceptions associated with the HIV/AIDS epidemic (Benefo, 2004). Stein (2001) further suggests that information about the HIV/AIDS epidemic provided by media is a more commonly cited resource than educational campaigns or interpersonal communication. Without affixing judgment, Nelkin argues that the media is a good source of health information, including HIV/AIDS, to the extent that it simplifies, popularises and interprets scientific information using reporting strategies that cover the controversies, drama, and human interest aspects of the disease with brevity, simplicity, and in a compelling manner (Nelkin, 1999). The media also goes beyond just communicating information, it also frames and mediates our cultural understandings, representations, and interpretations of a social phenomenon, for example, the HIV/AIDS epidemic.

Krishnan et al., (1997) argue that the media communicates to the public everyday metaphors and posits values as it challenges and interprets local custom, morality, and individual and collective preferences related to health and illness. The media also contributes to agenda-setting of important issues that inform everyday conversations and policy discussions.

The use of media by the TAC influenced setting of the HIV/AIDS policy agenda in South Africa. Denis McQuail, as quoted in Nelkin (1997), argued that the media can move issues to centre stage or keep them out of the public view, suggesting that the media serves as a filter through which people receive and interpret news and events. The information conveyed, its verbal and visual images contribute to

shaping the significance of events, public attitudes, and legitimatize or not public policy debates.

### 10.3 Media Coverage of the HIV/AIDS Epidemic in South Africa

The media has been recognised as an important disseminator of information about the social, political, and human dimensions of the HIV/AIDS epidemic in South Africa. (Brodie et al., 2004). Generally, most studies of the role of the media in the early years of the AIDS epidemic were critical, arguing that coverage tended to be superficial, simplistic, and celebrity-driven. (Garret, 2000; Moeller, 1999; Gibson, 1994; Connelly and McLeod, 2004). Treichler (1999) summed up criticisms of the quality of coverage when he suggested that the HIV/AIDS epidemic had generated an 'epidemic of signification', which negatively affected the full dimensions of the epidemic.

More specific to South Africa, studies by Media Tenor (2005); Stein (2001), and Shepperson (2000) found that there was an initial increase in news coverage of the HIV/AIDS epidemic in the post-apartheid South Africa. Jacobs and Johnson noted that,

> Characterised with few exceptions, by indifference to or lack of urgency as to the epidemic's impact, failure to systematically examine the reasons behind stigma and not engaging or seeking out the views of people living with HIV/AIDS, who if approached are presented as victims or denied any urgency. Coverage is also characterised by the virtual absence of the voice of the people, individuals living with HIV/AIDS, and those immediately affected (2006: 133).

Stein (2001) and Schoofs (2000) further criticised the media's early coverage of the HIV/AIDS epidemic for its failure to question the interaction between the disease and the bigger cultural, economic and, political discourses of the time. It has been argued that the early coverage of the epidemic actually help to facilitated the government's weak policy response which led to a victimisation of certain high risk groups including prostitutes, gays, blacks living in slums. Further, by inferring that HIV was not a disease that could affect anyone

regardless of their race, colour, class, or religion (Joffe, 1995; Cullian, 2001; Stein, 2003 and; Jacobs and Johnson, 2007).

### 10.4 The TAC and its Use of the Media

The TAC used the media as one of its key strategies for putting pressure on the South African government to develop a comprehensive response to HIV/AIDS that included evidence-based HIV/AIDS policies and treatment programmes. In planning its social mobilisation events, the TAC attempted to maximise media coverage by providing actual stories of HIV-infected individuals' fight for their lives. Through these human interest stories, the TAC built a core constituency among media correspondents.

Finlay argued that the media clearly aligned itself with the TAC which was led by PLWHA to the exclusion of reporting that might damage the movement's image (Finlay, 2005). Whenever possible, the TAC used high profile influential figures like Nelson Mandela as well as respected academics, professionals, and religious leaders to carry its message forward.

Finlay wrote about what he considered to be a growing anti-government bias in the media in terms of its reporting,

> Given the relative complexity of a public ARV treatment programme, the lack of resources and capacity in the newsroom, as well as the lack of widespread editorial-level policy thinking on HIV and AIDS coverage, how is it that the press has come to represent a position so strongly in opposition to the government policy. (Finlay, 2005)

The media reportedly had insider information that Mankahlana (he was a high profile figure in Mbeki's administration) died from an HIV/AIDS-related illness, in spite of his wife's denial to the contrary. It was not uncommon for families to deny AIDS-related deaths. Mark Gevisser, a journalist by profession wrote observed that, "Parks Mankahlana, had been 'vanquished by the antiretroviral drugs he was wrongly persuaded to consume,' killed by doctors who 'remain free to feed others the same drugs' (2007).

In defending Mbeki's stance on HIV/AIDS, Mankahlana was reported to have made a number of controversial statements about the causes and transmission of AIDS, as Cullinan suggested,

> The "does HIV cause AIDS" debate had the positive effect of encouraging journalists to study the science of HIV/AIDS – something that has been, and still is, sorely lacking in the national media (2001).
> Finlay adds,
>
> Nevertheless, media institutions do recognize the importance of covering HIV/AIDS. A lack of skills and in-house as well as budgetary and time constraints mean that this takes several forms, including: "relying on inexperienced journalists ('green journalists') to cover the story" (as quoted in Stein 2002; Delate 2003); relying on news services (such as SAPA or Health-e) for copy; creative cross-pollinating coverage, ... (Finlay, 2004).

Media reporting on HIV/AIDS was further complicated by the political controversy caused by Thabo Mbeki's view on HIV/AIDS and the implication of these views

for HIV/AIDS policy in South Africa. Understanding its influence of public perceptions, the TAC learned to exploit the print media whenever possible.

An early challenge in the dissemination of information concerning the HIV/AIDS epidemic was that media organisations did not have a stable of HIV/AIDS knowledge experts on their staffs. Finlay noted that,

> The lack of specialist knowledge is felt through all the levels of the newsroom, and the skills, awareness and sensitivities of the editor and sub-editor also plays an important part on how HIV/AIDS makes it into news (2004).

As noted by Anton Harber (2003), South African newsrooms had few experienced journalists, and more likely green generalists (Delate, 2003).

#### *10.4.1 "Bisho bungles Aids scheme"*

> *AS TEARS of pain rolled down 36-year-old Thembakazi Mjeje's face, her exhausted body racked by a persistent dry cough, heaved painfully on the grass mat near the hearth on her aunt's kitchen floor in Cikoli village in Lusikisiki. She was in intense pain, she told HIV/Aids adherence counsellor Nomini Mabena. Her aunt, Magobodela Mjeje, also sick herself, lamented the exit of medical volunteer group Medecins Sans Frontiers (MSF) last October, saying with their leaving they had taken all hope she had for help with her niece. "Watching her sit there knowing that there is no help on the way is very painful," she said. "I know that if that (white) doctor was still here he would have come and taken her away, she would not be suffering," she said, referring to MSF's Lusikisiki co-ordinator, Dr Hermann Reuter, who had helped run the programme. When MSF left the community of Lusikisiki in the Eastern Cape last year, Reuter had said: "We are handing over a whole package to the department, with all necessary structures to ensure continuity in place." Lusikisiki became the site for MSF's model of care because it had a high HIV prevalence. Reuter had described it as "completely unmatched" before they developed their four-year flagship programme, which eventually saw all 2200 people eligible for ARVs receiving them, with no waiting list. MSF's programme achieved universal access to anti-retroviral therapy and revolutionised traditional primary healthcare in what was one of the most under-resourced and disadvantaged communities.*

> *The programme had three pillars – a mobile team to support nurses at clinics; the recruitment of adherence counsellors; and strong community engagement to support the health system. "They (MSF doctors) came to see me once. If they were still here I would have been taken to hospital and would be in no pain. A Gateway Clinic nurse, who requested anonymity, said MSF adherence counsellors made follow-ups of everyone who tested positive. "Dr Reuter would go as far as carrying patients on his back to his car and into the hospital, just to ensure that they got the treatment they deserved." HIV-Aids Adherence Counsellors' Organisation (HAACO) co-ordinator Bavuyise Vimbani said the government had gone back on the agreement with MSF, by failing to absorb the MSF-initiated adherence counsellors organisation because it was not "provided for in their organogram". "The formation of HAACO was an exit strategy by MSF, to ensure that government took over an existing structure to ensure continuity."*

Makhubu has written massively on health for the *Daily Dispatch*.

According to Bavuyise Vimbani[57], Ntando Makhubu wrote and published the *Bisho bungles Aids Scheme* article without consulting with the tripartite alliance? , that is, HAACO, the TAC and MSF. In my interview with Vimbani, this is what he said about the article and the reporter;

> The journalist did not know what he was writing about. He was just piecing information together and misquoting people that he in some cases never spoke to. He didn't speak to me. Thembakazi Mjeje was not on the ARV programme. Makhubu just randomly picked the dying AIDS patient from the community... It's a ridiculous article... According to Makhubu, *"Dr Reuter would go as far as carrying patients on his back to his car and into the hospital, just to ensure that they got the treatment they deserved."* Dr. Reuter might have once or twice carried patients on his back, but these were exceptional cases and never a rule... Home-based carers are the ones who do home visits, and they are the ones who refer patients needing ARV drugs to us - HAACO and I am therefore sure that our counsellor was responding to a patient referred to her as a known HAACO counsellor deployed in that area. Ever-since MSF left, we never had a shortage of ARV drugs. Everything is so far running smoothly. We are ordering ARV drugs and other HIV and AIDS

[57] Bavuyise Vimbani started his career as a counsellor before joining MSF as an adherence counsellor and later became an Adherence Counsellor Coordinator. Vimbani is now the Project Coordinator of the HIV/AIDS Adherence Counsellors Organisation (HAACO).

> drugs and drugs for opportunistic infections as and when required and needed [emphasis added].

Simpiwe Ntantala (Interview, November 2007)[58] had also this to say about Makhubu' s article;

> As far as I know the patient referred to in the article was not on ARV drugs. In addition, the Good Hope clinic which is the closest clinic to the patient's home has a very poor infrastructure... From my knowledge, our adherence counsellor only went to visit the patient in her personal capacity and coincidentally met with the *Daily Dispatch* reporter. Most of the information is faulty. There is something wrong with it. The reporter had very little knowledge about what he was writing on. Sometimes you can see that he didn't understand the term that he was using [emphasis added].

According to Noloyiso Ntamehlo[59] HAACO was certainly not happy with the *Bisho bungle Aids Scheme* article. They had their own reasons for their unhappiness. Ntamehlo (Interview, November 2007) had this to say;

> According to one of the adherence counsellors, Thembakazi Mjeje had a lot of places that she stayed in. She was way too mobile. She never stayed in one place. This might have made it difficult for the adherence counsellors to keep track of her whether or not she was on ARV drugs. However, the TAC met with the Ward Councillor of Good Hope to investigate the issue about Thembakazi Mjeje, but it was too little too late. The woman passed away during TAC's investigative process. The truth was never found. If the woman was on the ARV programme then adherence counsellors must blame the Department of Health for not providing them with a vehicle to visit the patient. If there was a vehicle, this incident would not have resulted into the death of Mjeje... With regards the ARV Programme and in the light of the article by Makhubu, yes, there are some difficulties, but not everything has fallen apart. The DOH is struggling to cope with the demands of the programme. The

[58] Simpiwe Ntantala is the Office Manager/ Administrator of the HIV/AIDS Adherence Counsellor Organisation (HAACO). Ntantala is also an former Administrator of MSF. He was recruited by MSF in May 2005 and left MSF in October 2006, the same time when MSF was leaving Lusikisiki. He later came to join HAACO in November 2006 and has since played a very crucial role in the setting up of HAACO.

[59] Noloyiso Ntamehlo is the Campaign District Organiser of the Treatment Action Campaign in Lusikisiki

> problems that the department is facing are not new to us (TAC) or to adherence counsellors or even to MSF. We (TAC) keep on putting pressure on them and they (DOH) then see us as a pressure group, but when the work is done they feel happy that they have done some work [emphasis added].

While the truth was never found as Ntamehlo puts it, but the question is, why is she so neutral and sympathetic in expressing her side of the story? Ntamehlo does not want to say that Makhubu did not interview her or get her consent for publicising the story. At the same time she is defensive of the adherence counsellors, just in case there are to blame. She however does not find it a problem to expose the DOH. She might have been very careful in choosing her words, but, she made her point that the DOH is not doing so well. Her position is therefore not surprising. Vimbani puts it;

> TAC acts as a pressure group, pushing the DOH to respond to problems. For example, TAC will always make noise about the shortage of nurses, drivers, formula milk and the unavailability of doctors among many other issues. It also threatens the DOH with going to the media if it (DOH) fails to deliver or act on anything (Interview, November 2007).

Ntantala had also this to say;

> We (HAACO) use TAC to confront the DOH when there are crisis and dire problems. This is also want MSF used to do. HAACO has the first-hand knowledge of what is happening in clinics and hospitals. We are aware of the problems and issues which the DOH is always grappling with. The moment we see the DOH reluctant to act, or any other relevant department for that matter, we ask TAC to confront that department. Once we take the issue to TAC, it confronts the relevant department with all sorts of threats, including threatening to go to the media (Interview, November 2007) [emphasis added].

It is not surprising to learn why Ntamehlo, as the member and face of TAC in Lusikisiki, had to make sure that she just does not just rubbish the article by Makhubu. She had to be careful in choosing her words. The media is one of the TAC's tools which it uses to threaten and pressure the government to act. So,

they need the media and must therefore not dare spoil their relationship with the media.

Makhubu also states that;

> The programme had three pillars – a mobile team to support nurses at clinics; the recruitment of adherence counsellors; and strong community engagement to support the health system. The adherence counsellors system has been referred to as the backbone of the programme – the glue that held the system together according to MSF's final report. But the programme is on the brink of collapse. When government took over, it failed to absorb the adherence counsellors – community members trained by MSF to manage all key processes.

> *Option 1*
> The first option was that of the possibility of the department of health partially funding HAACO, thereby allowing HAACO to maintain its independence as an NGO. HAACO is aware that should the department fully fund it, or give a funding of anything above 50%, the adherence counsellor organisation will automatically loose its autonomy. "This will mean that the department will be calling the shots and HAACO's advocacy role will be compromised." As such, should this be considered as the only option, HAACO will negotiate that the department funds between 40-49% of its activities in order for HAACO to maintain its autonomy. It is important for HAACO to continue playing an advocacy role and pressure the department were and when necessary.

> *Option 2*
> The total absorption of HAACO by the department of health, the implication was the death/end of HAACO. According to Vimbani, HAACO is not at all in a position to entertain this option (Interview, November 2007).

> *Option 3*
> HAACO remains a NGO with its own funders and therefore receiving no funds from the department of health. This is the present situation. While this is still the case, HACCO is however in talks with the provincial department of health for a possible funding which in any case does not compromise its autonomy. The talks could not be done at district level because the district does not have the autonomy to engage in such talks and take a decision. The district

> can, however, fund HAACO activities which it does in partnership with the Treatment Action Campaign.

While HAACO would want to be funded by the department of health and at the same time make sure that it is autonomous and maintains its advocacy role with less influence from the department of health. This, according to Vimbani (Interview, November 2007) was the case in other provinces. KwaZulu-Natal was one such example. Adherence counsellors in this province therefore earn a monthly salary from the department of health of R2 500, while lay counsellor from Lusikisiki earn a monthly salary of R1 000 from the department of health. The lay counsellors are however paid through a local NGO which is run, totally funded and controlled by the department of health.

The battle against HIV/AIDS in other newspapers and also browsed through some reports. As such, his article is rooted on background assumptions of knowledge and evaluation, commonly referred to by scholars of the media as a frame (Jacobs and Johnson, 2007). According to Benford and Snow (1996), the concept of frames, derived from the work of Erving Goffman, denotes “schemas of interpretation” or “action-oriented sets of beliefs and meanings” that enable individuals to render meaningful occurrences in their life and the world at large. Hammond therefore writes;

> Using a frame, a journalist can represent events as part of a coherent larger reality within which readers and viewers can comprehend them. The frame adopted in a media account shapes the way particular details are presented and provides the broader context for the story. Frames are often presented in media analysis as something adopted relatively unreflectively by journalists and shared by their audience (2004).

Makhubu writes;

> Mjeje was tested and diagnosed HIV-positive in November 2004. In January 2005 her CD4 cell count stood at 270, and in February 2006 it was 250, but by September last year her CD4 cell count hit a low of 93.

Since 2003, MSF has been the major if not the only international non-governmental organisation (INGO) running and facilitating HIV tests together with government Voluntary Counselling Testing (VCT) centres in hospitals in Lusikisiki and surrounding villages. There are therefore very high chances that Thembakazi Mjeje was first tested by MSF. Hence, Makhubu notes, “They (MSF) came to see me once. If they were still here I would have been taken to the

### *10.4.2 Case Study 2*

**E Cape health dept. denies Aids treatment bungle**

*An HIV/Aids treatment programme is on track in Lusikisiki, contrary to media reports that it was bungled, the Eastern Cape health department said on Tuesday. Departmental spokesperson Sizwe Kupelo said the department took over the programme initiated by the Nelson Mandela Foundation and the NGO Médecins sans Frontières (MSF) in October last year.*

*The Daily Dispatch reported on Tuesday that a year after the handover, the programme was in "ruins".*

*An HIV-positive woman told the paper that when she was diagnosed with the disease she never thought "she would be stranded and left to die".*

*A Gateway Clinic nurse told the paper that the MSF adherence counsellors made follow-ups on everyone who tested positive. Since the government has taken over, the report said, communities are suffering as they see "very little" of adherence councillors.*

*Kupelo, in a statement, said adherence councillors who worked with MSF have formed an independent, community-based organisation and all counsellors are attached to clinics around Lusikisiki.*

*Since the NGO's handing-over of the programme, the department has employed additional staff including four doctors, two nurses, two pharmacy assistants and a data capturer, as a mobile team for the area.*

*"Rotational clinic visits by doctors is also an order of the day," he said. "Five vehicles are being utilised for clinic visits, mobile team outreach and to trace defaulters. We also wish to state that the HIV and Aids programme is sustained very well in Lusikisiki."*

*He said his department had instituted an investigation to locate the patient referred to in the Daily Dispatch article but was unsuccessful.*

*-- Sapa*

Case Study 2 vehemently denies the report in Case Study 1 that the HIV/AIDS Programme in Lusikisiki was bungled. It also correctly highlights the formation of the AIDS Programme and the taking over of the programme by the Department of Health. All might not be “very well” but the Department of Health is doing its

best to sustain and keep the programme up and running. Sizwe Kupelo, the spokesperson of the DOH presents a reflection of the struggling and working together of the government and NGOs at a community level in response to the AIDS crisis, while Makhubu, who is not well aware of such interaction, isolates the government in the form of the DOH and the NGOs. In any case, what I find very interesting is that, while Makhubu' s 'ground-breaking' story deserved a front-page headline, the DOH's response was seen as less important and the article was featured somewhere in the corner where one could hardly see it.

However, and as noted by Finlay (2004), this misrepresentation of facts by the media is not new. Shepperson (2000) also observes the messed up reporting of AZT in 1999. Against this backdrop of the lack of knowledge and awareness and, ignorance in the media around HIV/AIDS – ARV drugs and MTCT in particular, the question which remains unanswered is; How is it that the media, despite its noted and acknowledged errors, ignorance, lack of knowledge and awareness still so forcefully critical of the government's position on ARV drugs – and by implication favourable to the objectives of the TAC and AIDS activists – and still represented in the press?

**10.5 Media and the Complexities of providing ARV drugs**

The provision and administration of ARV drugs is delicate and very complex and yet at the centre of the media's reporting on HIV/AIDS and related issues. It is not as easy as how the TAC, AIDS activists in general and press put it. What makes the provision and administration of ARV drugs complex is the simple, ordinary and yet vexing questions that it raises which some players, most notably the media and AIDS activist tend to ignore and take so simple. Such questions include the overall cost of ARV drugs and the cost and training of human resources and the necessary physical infrastructure to administer an effective treatment programme. In addition, and as Finlay puts it; "What are the risks of scaling up? What are the possible lessons to be learnt from TB, termination of pregnancy (TOP) and MTCT intervention (2004)? These challenges and

implications with regard South Africa's belated ARV roll-out need to be considered and clearly understood by all players in the battle against HIV/AIDS. Those who are directly involved in the medical and scientific research are privileged as they are aware of these implications and challenges. Most people, who tend to be the majority who are not directly involved in the medical and scientific research, tend to be ignorant of these challenges and implications. This category includes the media and AIDS activists. They have no knowledge of the delicateness of ARV roll-out. The media in particular, which a lot of people rely on for information and education, are ignorant of the complexity of ARV roll-out and basic facts on HIV/AIDS. This is dangerous and destructive in the process of negotiating the provision and administration of ARV drugs. In referring to the lack of knowledge and ignorance in the newsroom about basic HIV/AIDS facts - ARV drugs in particular, Finlay writes;

> On World Aids Day, 2003, the preliminary findings of the quantitative part this research was one of several presentations given to a gathering of editors, journalists and government communicators, hosted by, among others the South African National Editors Forum. E-TV news head Joe Thloloe told the gathering that prior to attending, he had asked several journalists working at e-tv if they knew what key terms, such as 'CD4 count' and 'viral load' , often used in HIV/AIDS reporting meant. The responses showed, as he suggested, that there was a high level of ignorance in his newsroom about basic HIV/AIDS – and in particular ARV – terminology (2004).

Finlay goes on and further purports that;

> On 6 August 2004, at a report-back on the international AIDS conference held in Bangkok – which provoked much confused media coverage over the issue of Nevirapine, its efficacy and the government's position on this – South African Broadcast Cooperation (SABC) journalist Ida Jooste noted that it was the basic science of Nevirapine that was incorrectly reported by the press. Quoting from content items – including from SABC itself – Jooste said the issue of Nevirapine was "only understood by journalists some days back. It is a complex story." It is worth remembering that in 2002 Nevirapine was central to most news items dealing with HIV/AIDS, given the TAC's High Court challenge on the issue. It was clear that the basic tools for dealing with and understanding the

> evolving science of HIV/AIDS had yet been widely developed by the South African media (2004).

This distortion of basic HIV/AIDS facts – ARV drugs in particular, is not fair and is a serious cause for concern in the battle against HIV/AIDS in South Africa were the government is heavily criticised. The press has publicised a lot of articles and reports on ARV drugs, Nevirapine and PMTCT and yet the reporters, let alone the sub-editors and editors who approve the publication of the story, were ignorant of the basic facts of what they were publishing. These misrepresentation of facts, simple as some of them might be, have the power to misled people and to create confusion more especially here in South Africa where HIV/AIDS is highly politicised and as the press suggested, cost Madlala-Routledge her job.[60]

#### *10.5.1 Case Study 3*

**Lusikisiki Leads the ARV way**

> *The HIV/Aids programme initiated by Mèdecins sans Frontières in Lusikisiki is well on its way to reaching everyone in the sub-district who needs treatment, writes Kerry Cullinan.*
> *LUSIKISIKI in Transkei has just celebrated enrolling over 1100 Aids patients on anti-retroviral treatment, thus becoming the country's biggest rural treatment programme in the country.*
> *"The majority of people in South Africa can't spell Lusikisiki. They just know that it is in the bhundu…..*
> *The Lusikisiki programme was launched two years ago by Nelson Mandela, and is a partnership between the humanitarian organisation, Medicins sans Frontières, MSF, (Doctors without Borders), the Eastern Cape Health Department and the Nelson Mandela Foundation.*
> *An estimated 1 500 people in the area need ARV drugs, which means that the programme is well on its way to reaching all patients…..*
> *Patients wearing white T-shirts emblazoned with "viral load undetectable" sang modified freedom songs with Aids replacing*

[60] Some press articles suggesting that Nozizwe Madlala-Routledge was fired because of her stance on HIV and AIDS which was anti-Mbeki includes: Editorial, "Firing and AIDS Fighter" in *The New York Times*, August 14, 2007; Anne Penketh, "Mbeki says Minister was sacked for insubordination" *The Independent World*, August 13 2007; Sapa, "President breaks silence on Nozizwe" *Mail & Guardian*, August 11 2007; Michael Georgy, "Mbeki vulnerable after sacking Nozizwe" *Mail & Guardian*, August 14 2007; Sharon LaFraniere, "Mbeki fires aide who reshaped HIV policy" *International Herald Tribune*, August 9 2007; Piet van Niekerk, "Sacking of Cabinet's HIV fighter 'an insult'" and Sapa, "TAC launches fund for axed minister"

> *apartheid as the enemy and ARV drugs replacing AK47s as weapons of defence…..*
> *Meanwhile, Thomas described MSF's arrival at Lusikisiki as a blessing, adding that the hard work of St Elizabeth staff and MSF had "surpassed all expectations" (Health-e News Service).*

There is need for the media to acknowledge the efforts and interventions of government in the delivery and administration of ARV drugs at least in Lusikisiki' s HIV/AIDS Programme. The media in Lusikisiki makes it their mission that the government receives not credit for its efforts and interventions. The hard workers are only the TAC, MSF, HAACO and NMF. In passing, and careful of not giving praise to the government but to MSF and to the Nelson Mandela Foundation (NMF), Kerry Cullinan writes;

> The Lusikisiki programme was launched two years ago by Nelson Mandela, and is a partnership between the humanitarian organisation, Medicins sans Frontières, MSF, (Doctors without Borders), the Eastern Cape Health Department and the Nelson Mandela Foundation.

Correctly so, the HIV/AIDS Programme was initiated by MSF in partnership and with the blessing of the provincial Eastern Cape Department of Health and, with some financial support from NMF in Lusikisiki. The establishment of the programme was as a result of the cooperation between civil society in the form of MSF – an international NGO which later founded or gave birth to the local TAC and HAACO – and the provincial Eastern Cape Department of Health. Hermann Reuter concurs;

> The Lusikisiki programme set out with the difficult task of implementing antiretroviral therapy in one of the poorest and most densely populated rural areas of South Africa. It is a partnership between MSF (Doctors without Borders), the Nelson Mandela Foundation and the Eastern Cape Department of Health (2006).

What therefore makes the Lusikisiki case unique, successful and an example is how a working relationship was forged between two rivalries – civil society and the state. This is one of the crucial developments which the media needs to highlight and therefore owes it to the public and the government. This is also

were the crux of the success lies and the uniqueness of the programme. Lusikisiki's HIV/AIDS Programme is a model of best practice.

Cullinan quotes;

> "ARV drugs have become a political hot potato," Treatment Action Campaign (TAC) general secretary Sipho Mthathi told the crowd. "Some people say we need nutrition or vitamins or ARV drugs. But we are saying we want them all. The community of Lusikisiki has proved that ARV treatment works." You are living proof.

ARV drugs have surely become a political hot potato in the sense that all HIV/AIDS debates and a call by the TAC to the government to revamp its HIV/AIDS policy revolves around ARV drugs. But in Lusikisiki it is not the case anymore. Reuter in noting and acknowledging the unique and important role by the Department of Health writes;

> Lusikisiki has a population of about 150 000 people, with an estimated HIV infection rate of 15%, that is 22 500 people living with HIV. If 10% of these are immediately in need of ARV drugs, it means that 2 250 people are in need of ARV drugs. The Department of Health currently provides ARV drugs to 1529 patients (68% coverage in two years). Of these, 948 patients receive ARV drugs through twelve clinics and 581 through the hospital. Enrolment is increasing faster in the clinics because of multiple service points and services being integrated into general consultations and not dependent on HIV specific staff (2006).

Cullinan, in concluding his article puts the final nail on the coffin and drives his point home. Almost in the same vein with Reuter above, he writes;

> Aside from the hospital, there are 12 clinics to serve about 150 000 people and the MSF has ensured that the programme is primarily nurse-driven at clinic level so that it is sustainable when the organisation withdraws from the area at the end of 2006. Although officials from the national and provincial Health Department, including the health minister, were invited, none attended the ceremony.

The hospital which Cullinan is referring to in the article is St. Elisabeth and the ceremony he is also referring to was the accreditation of the hospital as an ARV administration point. I attended both the ceremony and a one-week community

social mobilisation prior to the ceremony which was run by the TAC. During the community mobilisation period, the TAC got as much support as it could from the DOH staff from almost all the 12 clinics in Lusikisiki. Even from the St. Elisabeth hospital where we had two days of community mobilisation.

### *10.5.2 Case Study 4*

**Transkei areas 'setting pace' for ARV rollout**

> *ANTI-RETROVIRAL rollout in an area of Transkei provided lessons that could be used to speed up delivery in other parts of the country, Deputy Health Minister Nozizwe Madlala-Routledge said yesterday. Madlala-Routledge made the comment after inspecting two clinics licensed to provide ARV drugs in Tsolo and Qumbu in the Mhlontlo municipal area. Earlier she was in Mthatha where she visited a regional training centre set up to manage the treatment of HIV/Aids and the use of anti-retrovirals.*
>
> *The two clinics, which started administering anti-retrovirals last year, service 175 patients.*
>
> *The number of patients has more than doubled in the past five months despite operating on limited resources, Madlala-Routledge said. Only one full-time doctor handles the ARV administration facilities in the rural municipality. The provincial government has come under pressure from HIV/Aids lobby groups to increase anti-retroviral rollout…..*
>
> *The department has been working with the Institute for Healthcare Improvement, a US-based non-governmental organisation, in trying to find ways to fast-track roll-out. Professor Pierre Barker said his organisation wanted to find "local solutions" to increase the number of people benefitting from ARV drugs. The deputy minister added that people had also complained about such other problems as lack of electricity and running water. The municipality would look into such issues, she said – DDC.*

What is particularly striking about the above case study is its neutrality, calmness and low tone. Why? Is it because Nozizwe Madlala-Routledge is the only government representative who turns to be publicly sympathetic to the AIDS activists in the form of the TAC? Or is it because of the way she cautiously chooses her words? Madlala-Routledge says everything that an AIDS activist - the TAC members in this case would love to hear. Madlala-Routledge puts it;

> Anti-retroviral rollout in an area of Transkei provided lessons that could be used to speed up delivery in other parts of the country, Deputy Health Minister Nozizwe Madlala-Routledge said yesterday.

The Deputy Health Minister highlights that the ARV roll-out in the Transkei provides South Africa with a lesson and yet more still needs to be done. As if this was not enough, Madlala-Routledge admits that the government is operating on limited resources and therefore something needs to be done. As a result, both the epidemic and the issues of resources are matters of great urgency. Madlala-Routledge states;

> "It's important for all of us to consider the urgency of this matter. It is an epidemic that is not only spreading, but also taking young lives." She said the success of the Mhlontlo ARV facilities could be attributed partly to the fact that patients who had been stabilised on ARV drugs were referred to primary health care institutions for further treatment. "We are dealing with a problem of limited resources," she said. "We are looking at how they are doing and seeing how we can take the lessons (we have learnt from the two sites) to other provinces and regions which are struggling."

Madlala-Routledge reiterates the issue of lessons to be learnt and drawn out of the Transkei ARV roll-out for other provinces and regions in the country. She is well aware of what her audience wants to hear. In addition, her visit to the Transkei – visiting two ARV sites and the Regional Training Centre (RTC) which manages the treatment of HIV/AIDS and the administration of ARV drugs – and her meticulously worded speech wins her all the support of AIDS activists. She left no stone unturned in her AIDS rhetoric, saying right things, at the right time, in the right place and to the right audience. Who then could be against her? Even the reporter could not find space in the article to criticise the government for that matter. The reporter writes;

> The deputy minister added that people had also complained about such other problems as lack of electricity and running water. The municipality would look into such issues, she said.

In other words, Madlala-Routledge is not only well aware of the stumbling blocks and complaints which hamper the delivery of ARV drugs and also the provision of

basic health care services but, she is also doing something about these issues. Highlighting issues of basic service delivery – the lack of electricity and running water in a poor province that is found wanting not only because of HIV/AIDS, but a dire need that people lack, is just putting the last nail into the coffin.

### *10.5.3 Case Study 5*

**Manuel questions AZT effect**

> *PRETORIA -- Anti-retroviral drugs did not "in any way" limit the spread of HIV and Aids, and could instead cause a number of other diseases, Finance Minister Trevor Manuel said yesterday…..*
> *Speaking at the launch here of a Census 1996 report on youth, he said the Aids debate in South Africa was misplaced because it focused on anti-retrovirals rather than education.*
> *"What anti-retrovirals don't do is to change the status of somebody. Nor do the anti-retrovirals on their own change the conduct of an individual who may be exceedingly promiscuous," he said. "It does not in any way limit the spread, but all of the focus is on anti-retrovirals, whereas in fact we need an educated population."The little I know about anti-retrovirals is that unless you maintain a very strict regime ... unless you have the facilities to deal with all of that ... they can pump you full of anti-retrovirals. "Sadly all you're going to do, because you are erratic, is to develop a series of drug-resistant diseases inside your body."*
> *What the country needed most, Manuel said, was educational interventions early in the lives of people … – Sapa.*

HIV/AIDS – ARV drugs in particular have undoubtedly become a "political hot potato". It depends who says what, when and how. Let it not be Mbeki or Tshabalala-Msimang. "Some people say we need nutrition or vitamins or ARV drugs. But we are saying we want them all" (Sipho Mthathi of the Treatment Action Campaign). It is ok if the TAC and its member or if the World Health Organisation (WHO) says nutritious food or vitamins are needed, but not Tshabalala-Msimang or Mbeki. The Minister of Finance – Trevor Manuel can say; Anti-retroviral drugs did not "in any way" limit the spread of HIV and Aids, and could instead cause a number of other diseases ..., but not Mbeki or Tshabalala-Msimang. This is how biased the TAC and its media friends are when it comes to HIV/AIDS in South Africa. It does not matter what Mbeki says on HIV/AIDS, he is

a denialist. It does not matter what Tshabalala-Msimang says, she is Dr. Beetroot.

In concurring with my observations and analysis Campbell and Gibbs write;

> Newspaper reports often blame individual government leaders for problems with HIV/AIDS management in South Africa, linking this either to lack of political will or lack of political leadership. This focus excluded a wider debate about what broader issues may be shaping government policy. The Minister of Health, Manto Tshabalala-Msimang, was a focal point of this kind of reporting.

According to Campbell and Gibbs (2008), "the lack of political will to implement national HIV/AIDS policy was often linked to the Health Minister's heterodox position on ARV drugs and her heavy emphasis on nutrition of people living with HIV."

The TAC set the HIV/AIDS reporting agenda for the South African media, making it their mission to convince reporters to cover the issues they were fighting for, such as access to ARV drugs or adequate government policies on the epidemic. Much of what South Africans and reporters learn about the science of HIV is taught not only by the TAC members, but by local NGOs, often through regular press conferences and through their statements on Mbeki and Tshabala-Msimang' s controversial remarks, made from the late 1990s through to 2002. This has as a result led to the media's misrepresentation of the disease. In Lusikisiki the media has therefore consistently misrepresented the perspectives of the poor and the real reality on the ground. Based on a thorough assessment on one the Eastern Cape Province's main newspaper – Daily Dispatch, I have in this chapter demonstrated the biasness of the media in their reports and knowledge construction on HIV/AIDS.

## Chapter 11: The Politics of Transition: From NGO to Government Ownership

NGOs have the potential to be a significant contributory agent in the development praxis in developing countries. In particular, international NGOs have the potential to open up space for inter-organizational alliances, greater community participation, and bilateral engagement between CSOs and local governmental agencies. These roles also have the potential to create dependency between local actors and international NGOs. In this chapter, I posit that MSF, in its attempts to create positive impact on HIV/AIDS health care policy and practice, created an unanticipated, unplanned dependency between a local CSO and provincial and local governmental agencies in Lusikisiki.

### 11.1 MSF Impact: Improved Access to HIV/AIDS Health Care Services

Before the arrival of MSF in Lusikisiki, HIV/AIDS counselling and testing services were accessible to only a few. In fact, counselling and testing was only available at St. Elizabeth's Hospital, the one hospital in Lusikisiki. By the time MSF exited Lusikisiki in October 2006, all twelve community clinics in Lusikisiki were providing these services. As a result, there was reportedly universal access to HIV testing and treatment with approximately 2200 people (MSF and DOH, 2006) being served. Additionally, improved knowledge among health care professionals and other care providers about the treatment and management of HIV/AIDS-infected persons was achieved and *task-shifting* practices between doctors and nurses were put in place. (MSF, 2005; MSF and DOH, 2006).

### 11.2 Creating Political Space

MSF played an essential role in creating space and opportunities for the engagement of other stakeholders, thus achieving a greater level of inclusiveness in the Lusikisiki community's response to the HIV/AIDS epidemic. As a result of MSF, the Lusikisiki TAC was funded, thus establishing one of its

first rural offices and providing the opportunity for meaningful collaboration with a local DOH agency.

The extent to which MSF contributed to a more TAC-friendly environment in Lusikisiki has been debated. The TAC partnership with MSF provided a voice and platform for TAC to make an impact in Lusikisiki; hence the relationship between the TAC and the local DOH in Lusikisiki was facilitated by MSF's presence.

> When MSF came here, we were not aware that they (?) there were also activists. We were only became aware when we were working with them that these people were also the TAC. Because that was new to us, at first we couldn't understand because their approach was to pressure. We couldn't understand why they were giving us pressure, because we felt that we should be working hand-in-hand, not to be pressurized as the Department of Health, but to be advised … In the middle of the programme, we realized that their importance was needed. It was necessary for TAC to be there (Interview with Dr. Hermann Reuter, August 2007).

MSF adapted the design of the Lusikisiki programme from the Khayelitsha experience to fit a rural context. Hence there was community participation in the implementation of the programme, but not in its design. Community engagement came through MSF's alliance with TAC via its community mobilisation activities. Based on the fact that community participation in the programme was through TAC's community mobilization efforts, specifically disseminating HIV/AIDS information and promoting rights to basic health care,

### 11.3 The MSF Impact on Health Policy

The MSF's impact on health policy, and health professional scope of practice in South Africa most notably was in the area of professional task-shifting. The Lusikisiki programme opened up opportunities for non-physician providers to provide essential HIV/AIDS related services (Interview with Mpho Mate, Eastern

Cape Department of Health staff member, August 2006).[61] According to this DOH informant, the policies established by MSF in Lusikisiki regarding professional task-shifting instigated an important health workforce discussion at the national level (Interview with Noxolo Mpinga, a Department of Health staff, March 2007).[62]

MSF was an organization involved in projects that assisted local governmental agencies with the professional knowledge necessary to improve the delivery of HIV/AIDS treatment services. MSF was an acknowledged expert in health services delivery that didn't have an agenda although Robins asserted, "whereas in the past MSF had sought to be neutral and non-partisan in its interventions, the conditions in South Africa forced the organization to take a more overtly political stand" (Robbins, 2004b:3).

Because of MSF's interest in influencing South African HIV/AIDS national policy, it could be argued that its South African agenda had a political agenda, "the model we were implementing [was] not just a medical model, it is a model for human rights and ARV drugs form part of this human right agenda." (Dr. Reuter, as quoted in IRIN-Plus News 2004). The MSF agenda included advocating for an HIV/AIDS treatment as a human right issue.

### 11.4 Challenges to Programme Sustainability

Most Lusikisiki case study informants believed that the MSF model was comprehensive and that it functioned well during the time it was operative in Lusikisiki, "from its inception, the programme was designed to be integrated into the health care system" (MSF 2006: 11). MSF came to Lusikisiki with a 3-year exit strategy but it ended up staying for slightly less than four years (Beresford, 2004). Seckielgin noted that, "although NGOs have been important actors in this field, they do not have the sort of agency required for sustainable long-term policy interventions in the context of HIV/AIDS" (2005: 6).

[61] Not her real name.
[62] Not her real name.

*Task-shifting* was central to the Lusikisiki model which was premised on nurses initiating ARV treatment while adherence counsellors preformed the education and intake function. The whole idea of task shifting changed with the departure of MSF, despite the shortage of doctors.

After the departure of MSF, it was unfortunate that the DOH was unable to seamlessly incorporate these counsellors into the model developed by MSF as *task-shifting* was perceived by DOH officials as a radical departure from existing scopes of practice of nurses. Unfortunately after MSF‘s departure from Lusikisiki, and the handover of the programme to the DOH, nurse management of ARV therapy was stopped. Nursing staff noted that its ability to manage ARV therapy was a major challenge faced by the clinics as it created an enrolment bottleneck for patients referred for testing and treatment.

Despite these challenges, the transition from MSF to a government-run programme was intended to be integrated into the local public health care system, "The only way to make this programme sustainable and replicable is to ensure that those solutions are urgently translated into policy changes at national and provincial levels" (MSF, 2006: 17).

The sustainability of the Lusikisiki HIV/AIDS Programme depended on the formal recognition that the changes initiated during MSF's tenure were integrated into the same model of comprehensive HIV/AIDS care developed by MSF (MSF, 2005: 18). If adherence counsellors were to be recognized as an integral part of the programme, their case needed to be elevated to a higher political level. As long as it remained a local matter it was unlikely that the national DOH would change its organogram. As long as these providers remained functional only in the Lusikisiki-based organization they would not have the needed capital to impact national AIDS policy.

The TAC therefore had a role to play in lobbying for the recognition of adherence counsellors and their inclusion as an integral team members of any HIV/AIDS treatment programme at the national level. In the same way they had lobbied for universal access to affordable ARV therapy.

It had been argued that for MSF to have had an impact on policy, it should have engaged itself with provincial policymakers as opposed to focusing on local level officials (Beresford, 2004). In either case, the new National Strategic Plan (NSP) of 2007-2011 included provisions for ARV therapy to be eventually delivered by nurses at primary health care clinics rather than from doctors at hospitals (MSF, 2007d). Accordingly, "the issue of task-shifting is already being discussed at national level" (Interview with Phelo Gaga, a Department of Health staff, February 2007).[63] However, it was the case that the national government needed to clarify its policies and make them explicit so that local governmental officials, programme managers, and clinic staff received clear guidance as opposed to individual interpretation (MSF, 2007d).

### 11.5 Shaping Local Power Relations

The introduction of nurse managed care in Lusikisiki during the MSF era had an impact on the power relations within the local health care delivery system. When the DOH took over the programme, it put an end to nurse management and the new found power and authority was taken away from the nurses, resulting in many resignations of nurses who sought employment elsewhere. "We therefore only had one option of leaving Lusikisiki as we had received substantial amount of training and experience from MSF and their adherence counsellors and from the TAC as well. We could easily get better, well-paying jobs in the private sector" (Interview with Bongeka Matutu and Zanele Mkumbuzi, February 2009).[64]

[63] Not his real name.
[64] Not the real name of these two nurses from s clinic in Lusikisiki.

MSF advocated for greater community participation in the programme. To accomplish this, it entrusted the TAC with the role of educating the community about its right to receive publicly delivered health care and enhanced its knowledge about HIV/AIDS, both its causes and treatment. The TAC also empowered and mobilized community members to speak-up and demand their right to basic health care services. The politicization of health care rights was something new to Lusikisiki residents, most were generally unaware of their constitutional rights under the post-apartheid constitution.

The establishment of the HIV/AIDS Programme in Lusikisiki created employment and volunteer opportunities for many people, including adherence counsellors and TAC activists.  As such, MSF contributed to the empowerment of Lusikisiki citizens both through job creation and meaningful community participation. The latter was particularly important for HIV-positive people as it was an opportunity for them to find themselves and also to help people in similar positions. This in turn helped to de-stigmatize HIV/AIDS and to shift the perception of PLWHA from the ‘walking dead’ to potential human resources, using their life experience and knowledge to help others under similar circumstances.

MSF changed the power balance in Lusikisiki by encouraging an active collaboration between civil society and the state. Civil society was given a voice and governance platform with regard to the HIV/AIDS epidemic in Lusikisiki. Besides the role of TAC, MSF also established another NGO in the form of the HAACO, which ended up having a central role in the HIV/AIDS programme, particularly after the departure of MSF.

### 11.6 Departure of MSF from Lusikisiki

All the key informants I interviewed expressed the significant loss of an important medical doctor, colleague, partner, and friend when MSF departed Lusikisiki. Dr. Reuter was the dominate figure in the HIV/AIDS programme, his name together with the TAC and MSF were used synonymously. When people spoke about

MSF and the TAC they often used the pronoun “he,” if not the name Dr. Reuter. He was a strength to many, a shoulder to lean on, a teacher, doctor, and a friend.

The adherence counsellors lost a mentor, TAC felt the loss of MSF and Dr. Reuter more than any other organization affiliated with the Lusikisiki programme. The TAC and MSF held events together, and even if MSF did not visibly take part in a TAC-organized demonstration, it provided encouragement in other ways. The TAC was able to access sensitive information that the DOH did not want to the public to access through MSF.

### 11.7 Mitigating MSF’s Departure

MSF acted as a transitioning agent for the Lusikisiki HIV/AIDS Programme, ensuring that cooperation continued between local NGOs and CSOs and the DOH. MSF made DOH reports available to the TAC and persuaded the DOH to accept the TAC as a programme partner. The TAC in turn pressured the DOH and threaten to go to the media to ensure that DOH would ensure the clinics were sufficiently resourced. The departure of MSF was not welcomed by all stakeholders both within and outside the programme. As soon as it became clear that the DOH was not willing to employ the adherence counsellors, which MSF considered to be the backbone of the programme, part of their exit strategy was to establish a new NGO to house the counsellors.

As a result the HAACO, composed of nineteen adherence counsellors, an administrator, a project coordinator and a general worker was established. The mission of this newly established NGO was to sustain the fundamental components of the HIV/AIDS programme. HAACO signed a memorandum of understanding (MOU) with the Eastern Cape Provincial Department of Health and became operative in August 2006 just prior to the departure of MSF (Interviews with; Reuter, Guilluame Jouquet and Philip Mokoena, August 2006; Vimbani, March 2007). The MOU stated that the provincial DOH would work to find a solution to incorporating the adherence counsellors into the on-going

treatment model. Unfortunately, the document was not legally binding. HAACO was scheduled to cease existing as an NGO in 2010. HAACO was 100 percent funded by Elton John Foundation via MSF (Interviews with Reuter and Guilluame Jouquet, August 2006). HAACO temporarily sustained the integrity of the programme by acting as an advocate with the DOH (Interviews with Reuter and Guilluame Jouquet, August 2006).

The clinics turned to HAACO and the TAC to assist them with liaising with the DOH. The DOH's responsibility was huge once the MSF departed Lusikisiki and HAACO now worked directly with DOH in organizing and reporting vital HIV/AIDS information. Based on data collected for this case study, HAACO had appropriately filled the shoes of MSF. Community members began to see HAACO as the same organisation as MSF, this was largely because HAACO was comprised of former MSF employees. HAACO occupied the same offices as MSF and performed the same critical role of providing the linkage between various partners and stakeholders associated with the programme.

HAACO acted as an important source of information for the TAC given the fact that it worked closely with the DOH and had first-hand access to HIV/AIDS statistics. Despite the unwillingness of the DOH to share this information with the TAC, HAACO was able to share the information they got from the DOH with the TAC, "we shared with the TAC and provided them with information about the programme and HIV/AIDS in the province and district which the DOH was reluctant to disclose" (Interview with Vimbani, November 2008). According to one adherence counsellor;

> "On the one hand we need to advocate for the patients, on the other hand we need to be neutral, not take sides. For example, in terms of the department and the community … But in terms of advocating for the patients, that is one of our main tasks. We must not compromise on that one because we need to make sure that everything is running smoothly and the communities are being treated the way they deserve. But now

> that we are working on DOH and directly with the department, it is not easy for us. (Interview with Thobile Mthembu, March 2007).[65]

HAACO engaged both in the politics of engagement and opposition in dealing with the DOH, its preference was for engagement. HAACO believed that through engagement as opposed to opposition they would have a more positive impact on programme outcomes. In this regard, the TAC and HAACO had different preferences in the ways in which they related to the DOH. Because HAACO chose a collaborative approach with the DOH, it played a facilitation role between the TAC and the DOH. TAC would have preferred that all Lusikisiki NGOs, including HAACO, unite with them in the politics of opposition with the DOH as they believed this was the only effective way to put pressure on the state to fulfil its role.

The leadership of HAACO restricted its counsellors in participating in public events supported by the TAC (Interview with Thobile Mthembu, March 2007). HAACO felt that *toyi-toyi* with the TAC against the state would jeopardize its working relationships with other partners (Interview with Thobile Mthembu, March 2007).

While the arrival of MSF created spaces for civil society's participation in Lusikisiki, its departure led to changes in these spaces. The TAC had been blocked from access to information from DOH which was illustrative of the lack of open communication between the two. In the alternative, the Committee for HIV/AIDS, STI, and TB (HAST) became the only viable local mechanism for HIV/AIDS-related participatory governance activities in Lusikisiki. Through HAST, local NGOs were given voice, "civil society is given an opportunity to voice its opinions in the forum, including local governance issues" (Interview with Nosiphelo Mfeketo, March 2007).[66]

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[65] Not the real name of the Adherence Counsellor.
[66] Not the real name of the Adherence Counsellor.

HAST meetings were held on a monthly basis. It appeared to be a symbolic venue in which NGOs and other civil society organizations and the DOH. Unfortunately, it was not reliable with regard to maintaining its regularly scheduled meeting schedule. On several occasions during my field work stakeholders would turn up for a scheduled meeting only to find that no DOH representatives were present. It became increasingly clear that initiatives intended to promote citizen participation did not guarantee that a participatory governance process would be achieved. It was reported by a number of community members that they were deeply frustrated by the lack of interest shown by the DOH.

### 11.8 AIDS Council as a Mechanism for Participatory Governance

The Eastern Cape AIDS Council (ECAC) was housed under the South African National AIDS Council (SANAC) and advised the provincial government on policy related to HIV and AIDS and brought together a variety of stakeholders to monitor, evaluate, and coordinate HIV/AIDS-related activities. Stakeholders include various NGOs, CSOs, sometimes including the TAC, and a range of governmental agencies. The local AIDS Council was intended to have the same functions at the local level.

The development of the local AIDS Council in the Quakeni LSA, to which Lusikisiki belongs, was still technically operative, although the Council was not functional during the time of my fieldwork. The idea of a local AIDS Council in Lusikisiki was illusory as expressed by TAC members, “the problem with the establishment of local AIDS Councils is that the bulk of funding for such initiative comes from the government … we all know that the government operates at a snail’s pace” (Interview with Mbulelo Kutu, June 2007).

To summarize, the Lusikisiki HIV/AIDS programme illustrates the fact that the politics of governance can vary significantly depending on the actors involved at different geographic and political levels. The partnership with an international

NGO that brought with it funding and  expert knowledge was essential in bringing about needed changes to the local health care delivery system and governance structure at the local level, MSF provided the resources needed allow the community to meaningfully participate in HIV/AIDS programming and the governance process.

Likewise, the departure of MSF from Lusikisiki meant that operational changes occurred, included a shift in the local power relations between civil society and governmental agencies. It could be argued that the departure of MSF led certain programme elements to cease to exist, "the major problem is that the ARV roll-out in Lusikisiki [was] dependent on MSF for expertise and resources" (Beresford, 2004: 37). Many of the informants in this case study felt that the MSF left too soon, that the programme was still in its infancy and therefore dependent on MSF's professional and financial support. Furthermore, with the departure of MSF, some of the political leverage for influencing public policy left as well.

It is evident that MSF's main objective in Lusikisiki was to prove that an HIV/AIDS treatment programme was possible in a remote rural area in South Africa and therefore to confirm that a feasible model was possible in other impoverished rural areas.

In the following chapter, I present concluding remarks and observations... I bring together various arguments and reflect on the key issues that relate to the treatment trends and political and strategic dynamics that shaped the interactions and partnerships between the state, local NGO/SGOs, international NGOs, and a representative rural community in the development discourse process.

## Chapter 12: Conclusion

While international donor aid to non-government organisations (NGOs) has become a central albeit much debated issue in development assistance, the rapid increase among these organisations in supporting the democratisation of African countries within a framework of good governance, social and economic development, poverty alleviation, gender equality, green peace, and HIV/AIDS treatment, continues to grow. The respective roles of international and local NGOs are complex to understand and equally complex to manage. Developing countries have been the recipients of actions undertaken by a number of key international donors to scale-up their global response to the HIV/AIDS epidemic.

Many bilateral and multi-lateral donors including the Presidential' s Emergency Plan for AIDS Relief (PEPFAR), United States Agency for International Development (USAID), and the Global Fund (GF) and humanitarian organisations such as *Medicine Sans Frontières* commonly known as Doctors Without Borders (MSF), have all provided significant resources to fight the HIV/AIDS epidemic. NGOs have been and continue to be at the centre of the response to the AIDS epidemic. The increase in numbers of NGOs at both at local and international levels, has helped to curb the spread of HIV/AIDS.

While good intentioned and generally effective, international NGO involvement raises a number questions such as whose interests are they representing? To whom are they accountable, e.g., local communities, governments, or funding agencies? Are funds provided without condition and/or strings attached? Are the resulting local partnerships equal? Have internationally-sponsored NGOs been able to sustain initial successes achieved?

This thesis has attempted to shed light on these questions, guided by the widely publicized success of the HIV/AIDS intervention programme in Lusikisiki spearheaded by an international NGO, Mèdecins Sans Frontiéres (MSF) in a

tripartite alliance with a local CSO, the Treatment Action Campaign (TAC), and a governmental agency, the Eastern Cape Department of Health. The thesis further describes the political dynamics that shaped the successes of the Lusikisiki project against a globally viewed tussle between parts of civil society and the South African government. It presents a contemporary history lesson in understanding what these intentional relationships can teach us about the complex nature of interactions between the state and NGOs in rural South Africa.

Specifically, this thesis has examined the social, political, and cultural dynamics operating within and surrounding an HIV/AIDS programme in Lusikisiki, a rural community in the Eastern Cape Province of South Africa. In particular, it has examined the roles and contributions of four primary organisational actors. Through a review of the extant literature germane to the study's theoretical argument, key informant interviews, and participant observation, the thesis sought to unravel, explain, and interpret the inter-organisational tensions, complexities, and strategies that were highly influential to the successes and challenges faced by the Lusikisiki HIV/AIDS programme.

The starting point for this thesis was to place the Lusikisiki programme in the broader socio-political context of South Africa's national HIV/AIDS policy and the subsequent political activities that ensued as a result of the delayed implementation of mother-to-child HIV/AIDS prevention programme as well as universal access to publicly-sponsored ARV therapy for PLWHA. These delays occurred in spite of the High Court's decision that to deny treatment was a violation of the South African Constitution (Kahn, 2002; Hartley, 2003). The thesis has put forward an argument that through social mobilisation, a treatment literacy programme, and use of anti-apartheid liberation songs and slogans by the TAC in partnership with the medical expertise, leadership, and funding provided by MSF, successful outcomes were achieved by the HIV/AIDS programme in Lusikisiki despite the oft times foot-dragging posture assumed by the Department of Health.

Critics of international development projects argue that foreign authorities use power to control knowledge (Escobar (2002). I argue that this power was typified in how PEPFAR superimpose its global policy agenda on the people of Lusikisiki while all but ignoring local knowledge, culture and indigenous health practices and beliefs. I discussed in Chapter 11 how these international funding organisations engaged in strategic translation to side-line local agendas in order to pursue their global agenda. Chapters 7, 8 and 9 discuss how religion, liberation rhetoric, and the media were used as instruments to validate foreign agendas and glorifying the development projects funded by foreign donors.

### 12.1 A Community United in Response to HIV/AIDS

The three primary organisational actors engaged in the Lusikisiki partnership shared the common objective of ensuring universal access to ARV drugs as part of a comprehensive HIV/AIDS programme in Lusikisiki. While the role of MSF was to provide medical care, expert knowledge, and HIV/AIDS treatment experience, its relationship with the DOH turned political as it also sought to influence HIV/AIDS treatment policy in South Africa. Some saw this expanded role as manipulative, particularly with regard to its local ally, the TAC. The partnership between MSF and the TAC was characterised by many faces that at times took on a chameleon-like character. Because MSF employed the TAC as its social mobilisation front, MSF was able to circumvent direct conflict with the DOH. As a result, MSF enjoyed a cooperative relationship with each entity. Likewise, MSF played a strategic information-channelling role for the TAC, providing information that allowed the TAC to engage in social and community mobilisation with vigour, using this information to pressure the DOH to cooperate and act responsibly on behalf of the community. The national Department of Health policies did not allow for task-shifting or the use of adherence counsellors as employed by MSF, but the provincial and local DOH bent these rules to allow MSF to run the programme as designed.

The TAC's duality of purpose was, on one hand, acting as a local service delivery NGO collaborating with the DOH through its HIV/AIDS literacy programme, whilst on the other hand, it was a rights-based social movement, using activism to pressure the government to speed up service delivery. The TAC therefore simultaneously employed the *politics of engagement* and the *politics of opposition*.

So too did the MSF that was first and foremost a volunteer medical organization providing expert knowledge and treatment to PLWHA. Beyond this role, it also had a policy agenda to pressure the South African government to update its HIV/AIDS treatment protocols through the integration community-based nurse-run HIV/AIDS treatment centres and the inclusion of lay adherence counsellors as critical components of publicly-sponsored HIV/AIDS treatment programmes. Simultaneously, MSF created opportunities for civil society in the form of the TAC and later HAACO to work in partnership with the local DOH and the community.

### 12.2 The Politics of Transition

The transition of the Lusikisiki HIV/AIDS programme, caused by the departure of MSF and the hand off of the programme to the Department of Health presented several challenges to the on-going sustainability of the programme. As an international NGO, MSF had the medical expertise, staff resource capacity, and financial support to run a successful programme. As a government run programme it became integrated into an already under-resourced public health care delivery system characterised by inefficiency, a shortage of human resources, and high level of bureaucracy regulated by static national policy.

The programme was significantly compromised by the loss of the nurse-run community clinic model when the DOH took over. Nurses were ordered to cease prescribing ARV drugs, while adherence counsellors, once seen as the backbone of the programme, had their role limited and reduced. The changing role of the adherence counsellors resulted in an enrolment bottleneck of ARV patients in the

clinic which experienced further losses of human resources as a large number of nurses left the Lusikisiki programme seeking better jobs elsewhere. Further, most importantly, the clinic staff experienced a loss of moral and financial support.

### 12.3 All Eyes on Lusikisiki

The new programme managers, now employees of the Eastern Cape DOH, together with the nurses and other employees, were frustrated by the DOH bureaucracy and having to work within a set of strict rules and regulations. The division of power and decision-making hierarchy limited their capacity to deliver care. As Lusikisiki had increasingly been known as a role model in South African HIV/AIDS treatment, the pressure on the local DOH escalated. The local DOH was aware that all eyes were on Lusikisiki and that any mistakes it made could lead to programme failure that would reflect poorly on the department. As a result, local DOH programme managers were invited to attend meetings and conferences around the country to give presentations about the success of the programme. It was noted that, "anti-retroviral rollout in an area of Transkei provided lessons that could be used to speed up delivery in other parts of the country" (*Daily Dispatch*, 15 July 2007).

### 12.4 The Mandela Factor

Another critical factor in explaining the touted successes of the Lusikisiki programme was its partnership with the Nelson Mandela Foundation (NMF), which provided both financial resources and the political legitimacy it needed. The involvement of the NMF was primarily as a financial supporter of the programme, initially through MSF which enabled MSF to embark more vigorously in the rural community of Lusikisiki. It was also a strategic partnership for MSF with a great deal of political cache. Working in partnership with an organisation not only bearing Mandela's name, but also strongly supported and 'owned' by Mandela, created an particular interest in the programme both regionally and internationally.

Mandela had previously attempted to speak up in national debates around HIV/AIDS and its treatment in South Africa, but his attempts did not receive a warm welcome from the ANC leadership, "Mandela became vocal ... and he silenced the moral police ... He couldn't be vocal decided Mbeki because he wasn't the president anymore" (Interview with Dr. Reuter, August 2006). According to Reuter, this could partially explain why Mandela decided to partner with MSF in the Lusikisiki programme. If he could not make his voice heard publicly, he could support others working in the field of HIV/AIDS. For MSF, the partnership with the NMF created a political space for Mandela while acting as a 'political shield' for the programme.

The involvement of Mandela also amounted to a blessing being conferred on the programme. Nelson Mandela was a national hero, perceived to be a living saint by many, he was iconic not only in South Africa, but in the entire world. For the Lusikisiki community, he was from their province (the former Transkei, a Bantustan homeland under apartheid). The fact that Nelson Mandela himself came to Lusikisiki to launch the programme in late 2003 and administered the first ARV drugs to a TAC member[67] was of great importance to the legitimacy of the programme. The community saw him administer the first ARV drugs to a TAC member thereby confirming that the drugs were not toxic as previously suggested by the government.

Besides Mandela, the other individual that conferred the most legitimacy on the programme was Dr. Hermann Reuter, a former TAC Western Cape Provincial Coordinator who later joined MSF to run the Khayelitsha programme. It was Reuter (as he was popularly known in Lusikisiki) who first discussed with Nelson Mandela the idea of establishing a rural HIV/AIDS treatment programme when Mandela visited the Khayelitsha programme in the Western Cape. Reuter did much of the planning, training and implementation of the programme himself. He

[67] Having interviewed Akhona Nstabula (the first ARV recipient in the programme), her story is elsewhere in the thesis, but it first appeared in NMF and MSF, *A Dialogue on ART Delivery* ... p13.

was the MSF Project Coordinator in Lusikisiki where he lived and worked until the formal hand-over of the programme to the DOH in October 2006.

### 12.5 The Bio-medical Approach of International Donors

The international donor community has largely focused its HIV/AIDS funding on a bio-medical interventionist approach with the goal of stemming the spread and resulting mortality associated with the disease. HIV/AIDS treatment using an ARV therapeutic regimen is based on the most rigorous and current evidence for treating HIV/AIDS. Because of the evidence, it became the dominant funding strategy for the international donor community. For local NGOs whose mission was also to stop the spread of HIV/AIDS and reverse mortality statistics associated with the disease, to receive funding from international donors meant that they had to align their interventional approaches with the donors' priorities.

### 12.6 Insider Observations

According to Bornstein, one of the most formidable enemies in social development, or the 'citizen sector' is self-deception (David Bornstein, 2004). In his book, *How to Change the World: Social Entrepreneurs and the Power of New Ideas,* Bornstein posits that as one engages more intensely in the inner workings of the development enterprise, s/he can develop a warped sense of reality. Terms such as monitoring and evaluation, indicators, inputs and outputs, take on a particular meaning that can spell goal achievement and positive impact (or not). There is no HIV/AIDS-related NGO or government agency annual report which does not seek to celebrate its achievements and overall impact. Bornstein (2004) suggests that the impact of NGOs most often falls far short from the numbers they produce. My observation as an insider participant observer is that we often miss the mark because we repeat the same mistakes or worse yet, rely on faulty assumptions. The following four assumptions fall into this category.

### 12.7 Externally-imposed donor standards and practices are transferable across cultural contexts

Foreign-imposed, culturally-insensitive policies and practices are a major cause for concern when applied to a local context. For example, one of the major reasons for the failure of initiatives such as condom use, healthy lifestyles, and medicalization of disease, is that they do not take into account the cultural context of the population being targeted for the intervention. Targeted groups are simply expected to adopt practices that have developed in far-away lands "for their own good". For example, educating people about the transmission of HIV/AIDS, about condoms, abstinence (Abstain, Be faithful, Condomise (ABC)), PMTCT, and other preventative measures, without attention to cultural and religious values, beliefs, and norms, is not sufficient. These interventions do not automatically lead people to be responsible and thereby reduce the spread of HIV/AIDS. Education about HIV/AIDS and its dangers can be of little use, meaningless, and worse yet, ineffective, if it is not integrated and grounded into the cultural and religious belief systems of a population.

Steinburg (2008) in his book, *Three-Letter Plague: A young man's journey through a great epidemic* discusses how Dr. Reuter struggled to have achieve community acceptance of the MSF programme due to its conflict with local cultural belief systems, values, and rituals. Govere (2005) also argued this point in the context of HIV/AIDS education and prevention strategies;

> Education is a much debated topic more especially when we talk about HIV/AIDS. One is tempted immediately to think of the talk about the prevention of the disease by advocating the use of condoms. In the *ubuntu-hunhu* world view, education involves much broader topics, all of which are interconnected. In fact, education is an on-going process which is part of an indivisible whole. It is, therefore, not treated as a special and separate entity needing special attention. Among many other opportunities, rites, rituals, ceremonies and gatherings provide ideal opportunities to educate (2005: 45).

### 12.8 Change in the Funding Priorities of International Donors

As discussed in this thesis, PEPFAR has shifted its funding model from directly funding of community-based NGOs to funding programme strengthening through new forms of NGOs that provide technical assistance. As such, through the shift of funding model and focus, not only have the local NGOs supporting communities had to drastically scale down their operations, if not close down completely, but communities have been left in the lurch, without alternative source of support. PEPFAR has continued to fund local projects through a hybrid model of funding which supports HIV/AIDS initiatives at district and sub-district levels. There are many examples of projects where no preparation was made for the day that international funding would cease. The TAC is one such organisation which has closed some of its branches and offices across the country due to funding problems.

### 12.9 Capacity-Building as an Ideal

Because local NGOs were able to build capacity through partnerships with international NGOs and funding from international donors, local NGOs have little choice but to follow the agendas set by international NGOs and donors if they wish to survive. An assessment of about 430 health facilities across the Eastern Cape and KwaZulu-Natal provinces in which I directly work as Monitoring and Evaluation Advisor, showed little significant improvement (Furlong and Ball, 2005; Parikh and Whiteside, 2007). Regardless, international NGOs such as PEPFAR continue to provide millions of dollars for HIV/AIDS development and intervention projects.

In conclusion, as discussed in the chapter on *AIDS, Governance and Civil Society*, democratic governance results from a process of interaction between various interest groups. This interaction should be seen as central to the politics of good governance. In Lusikisiki, the politics of governance in the context of HIV/AIDS was largely played out within and between the tripartite alliance between MSF, the TAC and the DOH. As Migdal argued in 2001, there are

various actors and coalitions which struggle over influence of governance, to have their opinions heard and to impact on policy-making and implementation. This was no less the case of Lusikisiki. The three central partners came to the alliance with different agendas and approaches and varying means to achieve them.

The successful implementation of the Lusikisiki HIV/AIDS programme can be explained by several key factors. First, there was a changing political climate in the dealing with the HIV/AIDS epidemic, including a new national plan for the roll-out of ARV drugs. Second, MSF attracted the support of Nelson Mandela, which opened up political space and provided it with what it called a “political shield‟ for the pilot programme in Lusikisiki. Lastly, as critics were claiming that they were unlikely to succeed in rolling out a rural treatment programme, MSF had a desire to prove their capacity to do so based their new programme on a successful urban model.

**Bibliography and Reference List**

Achmat, Z. (2001), Verbatim Transcript of address by Zackie Achmat, Chairperson of TAC to the AIDS in Context International Conference on HIV/AIDS, University of the Witwatersrand, April 7.

Achmat, Z. (2004), "HIV/AIDS and Human Rights: A New South African Struggle", *John Foster Lecture*, Barcelona.

ACORD and ACTIONAID. (1997), *Gender and HIV/ AIDS: Guidelines for integrating a gender focus into NGO work on HIV/ AIDS*.

Agrawal, A. (1995), "Dismantling the Divide Between Indigenous and Scientific Knowledge", in *Development and Change 26*, pp. 413-439.

Allen, T. and Thomas, A. (2000), *Poverty and Development in the 21st Century*, Oxford: Oxford University Press.

Anderson, B. (1981), *Imagined Communities: Reflection on the origins and spread of nationalism*,

Arce, A. and Long, L. (eds). (2000), *Anthropology, Development and Modernities*, London: Routledge.

Ballard, R., Habib, A. and Valodia, I (eds.). (2006), *Voices of Protest: social movements in post-apartheid South Africa*, South Africa: University of KwaZulu-Natal Press.

Banda, I. (2013), "Africa: ARV Intolerance - a Growing Problem for Aids Treatment in Africa."

Barnett, T. and Whiteside, A. (2002), *AIDS in the twenty-first Century*, New York: Palgrave MacMillan.

Bayer, R. and Oppenheimer, G. M. (2000), *AIDS Doctors: Voices from the Epidemic*, Oxford: Oxford University Press.

Bebbington, A. J. (1997). "New states, new NGOs? Crises and transitions among rural development NGOs in the Andean Region," *World Development* 25 (11), pp. 1755-1765.

Bebbington, A. J. (2004), "NGOs and uneven development: geographies of development intervention", in *Progress in Human Geography* 28(6), pp. 725-745.

Bebbington, A. J., Hickey, S. and Mitlin, D. (2008), "Introduction: can NGOs make a difference? The challenge of development alternatives", in: A. J.

Bebbington, A. J., Hickey, S & Mitlin, D. C (eds.), *Can NGOs Make a Difference? The Challenge of Development Alternatives,* London: Zed Books, pp. 3-37.

Benefo, K. D. (2004), 'The Mass Media and HIV/AIDS Prevention in Ghana', in *Journal of Health and Population in Developing Countries*, www.longwoods.com/content/17642 accessed 17/06/2010.

Benford, R. and Snow, D. (2000), "Framing Processes and Social Movements: An Overview and Assessment", in *Annual Review of Sociology 26*.

Beresford, B. (2004), "Pioneering Treatment Access in a Rural Area in South Africa", in *Development Update*, Vol. 4, No. 3, pp. 277-291.

Billis, D. (2003), "Partnership: a policy in search of implementation", in *Organising Public and Voluntary Agencies,* London: Routledge.

Billis, D. and MacKeith, J. (1993), *Organising NGOs: challenges and trends in the management of overseas aid,* London: Centre for Voluntary Organisation, London School of Economics.

Blumer, H. (1969), *Symbolic Interactionism: Perspective and Method*, University of California Press.

Bob, C. (2005), *The Marketing of Rebellion: Insurgents, Media and International Activism*, Cambridge: Cambridge University Press.

Bond, P. (2001), "The IMF and World Bank Reconsidered", in Coetzee, J. K., et al. (Eds.), *Development, Theory, Policy and Practice*, South Africa: Cape Town University Press.

Bornstein, L. (2003), 'Management Standards and Development Practice in the South African Aid Chain', in *Public Administration and Development* 23(5), pp.1-12.

Bornstein, E. (2005), *The Spirit of Development. Protestant NGOs, Morality and Economics in Zimbabwe*, Stanford: Stanford University Press.

Boulle, J. and Avafia. T. (2005), *Treatment Action Campaign (TAC) Evaluation*, (29 June 2005).

Brodhead, T. and O'Malley, J. (1989), NGOs and Third World development: opportunities and constraints, paper presented at the World Health Organization Global Program on AIDS Management Committee meeting, pp. 6-8.

Brodie, M., et al., (2004), 'AIDS at 21: Media Coverage of the HIV Epidemic 1981-2002', www.kff.org/kaiserpolls/7023.cfm, accessed 10/07/2010.

Brohman, J. (1996), *Popular Development Rethinking the Theory and Practice of Development*, Oxford: Blackwell Publishers Ltd.

Brown, D. (no date), ''Group Awarded AIDS grant despite negative appraisal the ABC of HIV Prevention", available at www.avert.org/abc-hiv.htm.

Brown, L.D. (1990), "Bridging organizations and sustainable development", in *IDR Working Paper no 8*, Boston, M.A.: Institute for Development Research.

Brown, L. D. and Korten, D. C. (1989), *The role of voluntary organizations in development*, Concept paper prepared for the World Bank.

Bryman, A. (1988), *Quantity and quality in social research*. London, Boston. Unwin Hyman publications.

Byerly, I. B. (1998), "Mirror, Mediation and Prophet: The Music Indaba of Late Apartheid South Africa," in *Ethnomusicology, Vol. 42, No. 1*, 1998, pp1-44.

Camay, P. and Gordon, A.J. (2004), *Evolving Democratic Governance in South Africa*, Johannesburg: The Cooperative for Research and Education (CORE).

Cameron, E. (2005). *Witness to AIDS*, London: Tauris.

Campbell, P. (1998), *Relations between Southern and Northern NGOs in the context of sustainability, participation and partnership in development,* Unpublished discussion paper prepared by International Committee for Voluntary Agencies (ICVA) Working Group on Development Issues.

Campbell, C. (2003), *'Letting them Die': Why HIV Intervention Fail*, Oxford: James Currey.

Campbell, C. and Gibbs, A. (2008), "Representations of HIV/AIDS management in South African newspapers", in *African Journal of AIDS Study*, 7 (2), pp. 195-208.

Carroll, T. F. (1992), *Intermediary NGO's: The Supporting Link in Grassroots Development*, Hartfold, CT: Kumarian Press.

Chamber, R. and Pettit, J. (2004), 'Shifting Power to Make a Difference', in Grove, L. G. et al (Eds.), *Inclusive Aid: Changing Power and Relationships in International Development*, Sterling, VA: Earthscan.

Chikane, F (2012). *Eight Days in September: The Removal of Thabo Mbeki*, Picador Africa: South Africa).

Chikane, F (2013). *The Things that Could not be said: From A{iads} to Z{imbabwe},* Picador Africa: South Africa.

Chirambo, K. (2006), *Democratisation in the Age of AIDS: Understanding the Political Implications*. 1st ed. Cape Town: Institute for Democracy in South Africa.

Chopra, M. and Ford, N. (2005), "Scaling up health promotion intervention in the area of HIV/AIDS: challenges for rights based approaches", in *Health Promotion International*, Vol. 20, No. 4, pp. 383-390.

Clarke, G. (1998), "Non-governmental organizations (NGOs) and politics in the developing world", in *Political Studies* XLVI, pp. 36-52.

Clifford, J, and Marcus, G. (Eds) (1986), *Writing culture: The poetics and politics of ethnography*. Berkeley, CA: University of California Press.

CNN. (1999, 6th May), 'Cash-strapped S. African government cuts AIDS drug programs.'

Coleman, G. (1992), 'Monitoring and Evaluation in Agricultural and Rural Development Projects', *Journal of International Development* 4(5), pp. 497-510.

Commission of the European Communities-CEC. (1988), *The Future of Rural Society*, Brussels: CEC.

Connelly, M. and Macleod, C. (2003), 'Waging War: Discourse of HIV/AIDS in South African Media', in *African Journal of AIDS Research*, 2 (1), pp. 1-11.

Cornwall, A. (2007), "Buzzwords and fuzzwords: deconstructing development discourse", in *Development in Practice* 17(4-5), pp. 471-484.

COSATU, (2006). 8 resolutions on HIV/AIDS. COSATU 7th national congress resolutions, in www.cosatu.org.za/congress/cong2008/resoce.htm#8

Cracknell, B. E. (2000), *Evaluating Development Aid: Issues, problems and solutions,* New Delhi: Sage.

Crais, C. C. (1992), *The Making of the Colonial Order: white supremacy and black resistance in the Eastern Cape, 1770-1865*, Johannesburg: Witwatersrand University Press.

Crane, S. and Carswell, J. S. (1990), ' Review and assessment of NGO-based STD/ AIDS education and prevention projects for marginalised groups', in *Paper presented at the International Conference on Assessing AIDS Prevention*, Montreux, Switzerland, 29 October-1 November 1990.

Crewe, M. (1992), *AIDS in South Africa: The myth and reality*, Harmandworth, England: Penguim.

Crewe, M. (2000), 'South Africa: Touched by the vengeance of AIDS', in *South African Journal of International Affairs 7:2.*

Crewe, E. and Harrison, E. (1998), *Whose development? An Ethnography of Aid*. London: Zed Books.

Cullinan, K. (2002), “The Media and HIV/AIDS. A blessing and a curse”, in *AIDS Bulletin*.

Cullinan, K. (2004), “Behaving ‘better'? The media, HIV/AIDS and stigma”, in *Center for the Study of AIDS Forum*.

Cullinan, K. (2005), “Narrating from the body: Health and the state of our nation”, in *Health-e News Agency*.

Degnbol-Martinussen, J. and Engberg-Pedersen, P. (2003), *Aid: Understanding International Development Cooperation*, New York: Zed Books.

De Waal, A. (2006), *AIDS and Power: Why There Is No Political Crisis – Yet*, London: Zed Books.

De Wet, G. (2004), “Agenda setting and HIV/AIDS news sources, implications for journalism education: An exploratory study”, in *Ecquid Novi* 25 (1).

Dichter, T. (1989), “Issues critical to a shift in responsibilities between U.S. PVOs and Southern NGOs”, in *Paper to the Advisory Committee on Voluntary Foreign Aid, The DONOR* December 6, 1989.

Dietrich, W.J. (2010), The Politics of PEPFAR: The President’s Emergency Plan for AIDS Relief.

Downing, R. (2005), *As They See It: The Development of the African AIDS Discourse*. London: Adonis and Abbey.

Dutta, M. J. (2011), Communicating Social Changes: structure, culture and agency, New York: Routledge.

Easterly, W. (2006), *The White Man’s Burden: Why the West’s efforts to aid the rest have done so much ill and so little good*, New York: Penguin.

Easterly, W. (2013), *The Tyranny of Experts: economists, dictators, and the forgotten rights of the poor*, New York: Basic Books.

Ebrahim, A. (2003), "Accountability in practice: mechanisms for NGOs", in *World Development*, 31(5), 2003: 813-829.

ECAC (2005). *Annual report on the HIV&AIDS epidemic.* King Williamstown: Eastern Cape AIDS Council.

Edgar, B. and Saphire, H. (2000), *African Apocalypse: the Story of Nontetha Nkwenkwe, a 20th Century South African Prophet*. Wits Press: Johannesburg.

Edwards, M. and Hulme, D. (1992), "Scaling up NGO impact on Development: learning from experience", in *Development in Practice*, Vol. 2, pp. 77-92.

Edwards, M. and Hulme, D. (1998), "Too close for comfort? The Impact of Official Aid on Nongovernmental organizations", in *Current Issues in Comparative Education*, 1 (1), pp. 6-28.

Eisner, E.W. (2004), Educational reform and the ecology of schooling, in Ornstein, A.C. and Behar, L.S. (Eds.) *Contemporary Issues in Curriculum,* pp. 390-402). Needham Heights, MA: Allyn and Bacon.

Elbers, W. and Arts, B. (2011), "Keeping body and soul together: southern NGOs' strategic responses to donor constraints", *International Review of Administrative Sciences* 77(4), pp. 713-732.

Epstein, S. (2003). *AIDS in South Africa: The Invisible Cure,* New York Reviews of Books, 17 July 2003.

Escobar, A. (1988), "Power and Visibility: Development and Intevention of Management of the Third World", in *Cultural Anthropology, Vol. 3*, pp. 428-443.

Escobar, A. (1991), "Anthropology and the Development Encounter: the Making and Marketing of Development Anthropology", in *American Ethnologist 18 (4)*, pp. 16-40; *Ethics 9 (1)*, pp. 1-15.

Escobar, A. (1995), *Encountering Development: The Making and Unmaking of the Third World*, Princeton, NJ: Princeton University Press.

Escobar, A. (2000), "Beyond the Search for a Paradigm? Post-development and Beyond", in *Development 43 (4),* pp. 11-14.

Escobar, A. (2001), "*Culture Sits in Places. Reflections on Globalism and Subaltern Strategies of Globalization"* in Political Geography 20, pp. 139-174.

Escobar, A. (2002), "The Problematization of Poverty: The Tale of Three Worlds and Development", in Schech, S. & Haggis, J. (Eds.), *Development: A Cultural Studies Reader*, Blackwell Publishing: Oxford 0X41JF, UK.

Escobar, A. and Harcourt, W. (2002), "*The intersection of women, culture and development: visions for the future*," in Development 45 (1), pp. 7-14.

Evertz, S. H. (2010), *How Ideology Trumped Science: Why PEPFAR Has Failed to Meet its Potentia*l, Sponsored by the Council for Global Equity.

Farmer, P. (2005), *Pathologies of Power: Health, Human Rights, and the New War on the Poor*, London: University of California Press.

Farrington, J. and Bebbington, A. with Wellard, K. and Lewis, D. (1993), *Reluctant partners?: non-governmental organizations, the state and sustainable agricultural development,* London: Routledge.

Fassin, D. (2007), When Bodies Remember: Experiences and politics of AIDS in South Africa, London and Berkley: University of Carlifornia Press.

Ferguson, J. (1990), *The anti-politics machine: 'development', depoliticization and bureaucratic power in Lesotho*, Cambridge: Cambridge University Press.
Ferguson, J. (1997), "Development and Bureaucratic Power in Lesotho", in Rahnenna, M. & Bavtra, V. (Eds.), *The Post Development Reader*, London: Zed Book.

Feyerabend, P.K. (1975), *Against Method: Outline of An Anarchistic Theory of Knowledge*, London: New Left Books.

Findlay, A. (2004), "Shaping the conflict: factors influencing the representation of conflict around HIV/AIDS policy in the South African press," *Communicare* 23 (2), pp. 68-93.

Fontana, A. and Frey, J. (1994), The interview: From structure questions to negotiated text. In Denzin, N. and Lincoln, Y. (Eds.) *Handbook of qualitative research.* Thousand Oaks: Sage Publication, Inc., pp. 645-673.

Foucault, M. (1972), *The Archaeology of Knowledge: the Discourse on Language*, New York: Tavistock Publications Limited.

Foucault, M. (1981), The order of disorder; inaugural lecture at the College de France given 2nd Dec 1970 in Yound, R. (Ed), *Untying the text: A post-structuralist reader*, Boston: Routledge and Kegan Paul.

Fourie, P. (2006), *The Political Management of HIV and AIDS in South Africa: one burden too many?* New York: Palgrave Macmillan.

Fowler, A. (1995), "Assessing NGO Performance: Difficulties, dilemmas and a way ahead", in Michael Edwards and David Hulme (eds.) *Non-governmental Organizations – Performance and Accountability*, London: Earthscan.

Fowler, A. (1997), *Striking a balance: a guide to enhancing the effectiveness of non-governmental organisations in international development*, London: Earthscan.

Fowler, A. (1998), "Authentic NGDO Partnerships", in *The New Polict Agenda for International*.

Fowler, A. (2000), "NGO futures: beyond aid: NGDO values and the fourth position", *Third World Quarterly* 21(4), pp. 589-603.

Fowler, A. (2011), "Development NGOs", in M. Edwards (ed.), *The Oxford Handbook of Civil Society*, Oxford and New York: Oxford University Press.

Friedman, S. (2006), *Participatory governance and citizen action in post-apartheid South Africa*, Discussion Paper: International Institute for Labour Studies.

Friedman, S. and Mottiar, S. (2004), *A Moral to the Tale: The Treatment Action Campaign and the Politics of HIV/AIDS*, Durban, South Africa: University of KwaZulu-Natal, School of Development Studies.

Friedman, S. and Mottiar, S. (2004a), *REWARDING ENGAGEMENT?: The Treatment Action Campaign and the Politics of HIV/AIDS*, University of KwaZulu-Natal, Durban: School of Development Studies.

Friedman, S. and Mottiar, S. (2006), "Seeking the High Ground: The Treatment Action Campaign and the Politics of Morality," in Ballard, *et al*., (eds.), *Voices of Protest: Social Movements in the Post-Apartheid South Africa*, South Africa: University of KwaZulu-Natal Press.

Furlong, P. and Ball, K. (2005), "The More Things Change: AIDS and the state in South Africa 1987-2003", in Patterson, A. S (Ed.), *The African State and the AIDS Crisis*, England: Ashgate.

Galloway, M. (2001), *Telling the story of the century: how are journalists coping with reporting on HIV and AIDS in South Africa*, M.Phil Thesis, University of Stellenbosch.

Gardner, K. and Lewis, D. (1996), *Anthropology, Development and The Post Modern Challenge*, London: Pluto Press.

Garofalo, R. (1992), “Nelson Mandela, the Concerts: Mass Culture as Contested Terrain,” in Garafalo, R, (ed.), *Rockin’ the Boat: Mass Music and Mass Movements*, Boston: South End Press.

Garret, L. (2000), *You just signed his death warrant: AIDS politics and the journalists role*. International Conference onAIDS, Durban.

Gasper, D. (2000), ‘Evaluating the ‘Logical Framework Approach’: Towards learning-oriented development evaluation’, *Public Administration and Development* 20, pp. 17-28.

Gasper, D. (2002), ‘Overview of the Strengths and Weaknesses of Logframes’, unpublished paper. Gosling, Louisa and Mike Edwards (1995) *Toolkits: A practical guide to assessment, monitoring, review and evaluation*, London: Save the Children.

Geertz, C. (1973), *The Interpretations of Culture*, New York: Basic Books.

Gevisser, M. (2007), *The Dream Deferred: Thabo Mbeki*, Jeppestown: Jonathan Ball Publishers.

Ghanotakis, E. et al. (2009), Tackling HIV and gender-based violence in South Africa: how has PEPFAR responded and what implications for implementing organisations? in *Health Policy and Planning Advance Access*, Oxford: Oxford University Press with The London School of Hygiene and Tropical Medicine, June 2009.

Gibson, M. D. (1994), ‘AIDS and the Media’, in *AIDS Bulletin*, 4 (1), pp. 6-9.

Gill, L. (1997), “Power lines: the political context of nongovernmental organisation (NGO) activity in El Alto, Bolivia”, in *Journal o f Latin American Anthropology* 2(2), pp. 144-169.

Gillwald, A. (1993), “The public sphere, the media and democracy”, in *Transformation* 21, 1993, pp. 65-77.

Govere, F.M. (2011), *A Contextual Approach in Mitigating the Impact of HIV/AIDS: mitigation by the Church of the impact of HIV/AIDS*, (Germany: LAMBERT Academic Publishing GmbH & Co.KG.

Gordenker, L. and Weiss, T. G. (1996), ‘Pluralising global governance: analytical approaches and dimensions’, in Weiss, T. G. and Gordenker, L. (Eds.), *NGOs, the UN, and Global Governance*, London, UK; Boulder, CO: Lynne Rienner Publishers, Inc.

Gumede, W. M. (2005), *Thabo Mbeki and the Battle for the Soul of the ANC.* Cape Town: Zebra Press.

Habib, A. (2003), “State-civil society in the post apartheid South Africa,” in Daniel, J et al., (eds.) *State of the Nation. South Africa 2003-2004*, Cape Town: HSRC Press.

Habib, A. and Kotze, H**.** (2003), “Civil Society, Governance and Development in the Era of Globalisation: The South African Case,” in Mhone, G. & Edigheji, O., (eds.) *Governance in the New South Africa: The Challenges of Globalisation*, Lansdowne: University of Cape Town Press.

Hailey, J. (2000), “Indicators of identity: NGOs and the strategic imperative of assessing core values”, *Development in Practice* 10 (3-4), pp. 402-407.

Hall, S. (1996), Cultural studies: two paradigms in Storey, J (Ed.) *What are Cultural Studies? A Reader*, London: Arnold.

Hammersley, M. and Atkinson, P. (1983), Ethnography: Principles in Practice, London: Tavistock Publications.

Heller, P. (2001), “Moving the state: the politics of democratic decentralisation in Kerala, South Africa, and Porto Alergre,” in *Politics & Society*, Vol. 29, No. 1 (2001), pp131-163.

Henderson, L. S. (2002), ‘Selling Civil Society: Western Aid and the Nongovernmental Organisation Sector in Russia’, in *Current Issues in Comparative Education*, 1 (1), pp. 6-28.

Heywood, M. (2004), “Price of Denial,” *Development Update* 5:3, Online at http://www.tac.org.za/documents/priceofdenial.doc. Accessed on July 20, 2007.

Heywood, M. and Cornell, M. (2004), 'Human Rights and AIDS in South Africa: From Right Margin to Left Margin', in *Health and Human Rights 2:4*.

Heywood, M. (2007), Power, AIDS stigma and the law, Unpublished Mimeo.
Hodgetts, D. and Chamberlain, K. (2003), “Media and Health: a continuing concern for health psychology”, in *Journal of Health Psychology*, 11 (2), pp. 171-174.

Hickey, A., Ndlovu, N. and Guthrie, T. (2003), *Budgeting for HIV/AIDS in South Africa: Report on intergovernmental funding flows for an integrated response in the social sector*, IDHASA Budget Information Service. Retrieved from http://www.idasa.org.za

Hobart, M. (1993), An Anthropological Critique of Development: The Growth of Ignorance, London: Routledge.

Holland, J. and Blackman J. B. (1998), *Whose Voice? Participatory Research and Policy Change*, London: Intermediate Technology Publication.

Howes, M. (1992), 'Linking Paradigms and Practice: Key issues in the appraisal, monitoring and evaluation of British NGO projects', *Journal of International Development* 4, pp. 375-396.

HSRC. (2009), *South African National HIV Prevalence, Incidents, Behaviour and Communication Survey, 2008. A turning Tide Among Teenagers?* Pretoria: Human Science research Council. http://www.hsrc.ac.za/Document-3238.phtml

Hudock, A. C. (1995). *NGOs and Civil Society: Democracy by Proxy?* Malden, MA: Blackwell Publishers Inc.

Hulme, D. & Edwards, M. (1996), Too Close for Comfort?: NGOs, States and Donors, London: Macmillan.

Hulme, D. (2008), "Reflections on NGOs and development: the elephant, the dinosaur, several tigers, but no owl", in A. Bebbington, S. Hickey & D. Mitlin (eds.), *Can NGOs Make a Difference? The Challenge of Development Alternatives*, London and New York: Zed Books.

Jacobs, S. and Johnson, K. (2007), 'Media, Social Movements and the State: Competing Images of HIV/AIDS in South Africa', in *African Studies Quarterly*, Vol. 9 (4), pp. 127-148.

Joffe, H. (1995), 'Social representations of AIDS: towards issues of power', in *Papers on Social Representation*, 4 (1), pp. 29-40.

Jones, P. S. (2004a), 'Of Gifts and Return Gifts. Beyond the political and practical deficits of donor assistance', in *Development Update, Vol. 5, No. 2,* pp. 157-182.

Jones, P. S. (2004b), 'When „development" devastates: donor discourses, access to HIV/AIDS treatment in Africa and rethinking the landscape of development', in *Third World Quarterly*, *Vol.25, No.2*, pp. 385-404.

Jones, P. S. (2004c), "A Test of Governance": The politics of HIV/AIDS policy and rights-based struggles in South Africa," in *Political Geography 24*, pp. 419-447.

Johnson, C. and Soderholm, P. (1994), 'IGO-NGO relations and HIV/ AIDS: innovation or stalemate?', in *Third World Quarterly*, 16 (3), pp. 459-476.

Kalombo, D (2006), *“Treatment: A View from Government*,” Nelson Mandela Foundation. *Mèdecins sans Frontiéres*: *A Dialogue on ART Delivery*. At a dialogue on the delivery of antiretroviral treatment in resource-limited settings held at Maropeng, Cradle of Humankind, Gauteng, South Africa.

Kates, J. et al. (2008), *Financing the response to AIDS in-low and middle-income countries: international assistance from the G8, European Commission and other Donor Governments, 2007*. Joint Collaboration Kaiser Family Foundation and UNAIDS.

Kauffman, K. D. and Lindauer, D. L. (Eds.). (2004), *AIDS and South Africa: The Social Expression of a Pandemic*, New York: Palgrave Macmillan.

Klein, N. (2003), ‘Bush to NGOs: Watch Your Months’, in *Globe and Mail (Canada)*, June 20, 2003.

Kohn, D. (2005), “More HIV Funds to Promote Abstinence: Researchers Call Policy Misguided”, in *The Baltimore Sun*, December 10, 2005, available at www.actupny.org/reports/bush_abstinencefunding.htm.

Korten, D. (1995), *Getting to the 21st Century*, West Hartford: Kumarian Press.

Krishnan, S., et al. (1997), ‘Coverage of AIDS in popular African-American health magazines’ in *Health Communication*, Vol. 9 (3), pp. 273-288.

Lewis, D. J. (1998), “Partnership as process: Building an institutional ethnography of an inter-agency aquaculture project in Bangladesh”, in D. Mosse, J. Farrington and A. Drew (eds). *Development as a process: Concepts and methods for working with complexity* (London: Overseas Development Institute and New York: Routledge.

Lewis, D. (1998), “Development NGOs and the challenge of partnership: changing relations between North and South”, *Social Policy and Administration* 32(5), pp. 501-512.

Long, N. and Long, A**.** (Eds.). (1992), *Battlefields of Knowledge: The Interlocking of Theory and Practice in Social Research and Development*, London: Routledge.

Long, N. and Van Der Ploeg, J. D. (1989), “Demythologizing planned intervention: An actor perspective”, in *Sociologia Ruralis*, Vol. 29, No. 3/4, pp. 226–49.
Long, N. (2001), *Development Sociology: Actor Perspective*, London EC4P 4EE: Routledge.

M'da, Z. (2000), *In the Heart of Redness. Penguin: Cape Town Jeff Peires 1989 The Dead Will Arise*, Penguin: Nongqawuse and the Great Xhosa Cattle Killing. Indiana University Press: Bloomington

Madavo, C. (2000), *AIDS, Development and the Role Vital of Government*, Speech delivered at the 12th World AIDS Conference, Geneva, Switzerland, 30 June 2000.

May, J. (2001), "Meeting the Challenge? The Emerging Agenda for Poverty Reduction in Post-apartheid South Africa," in Wilson, *et al*., (Eds.), *Poverty Reduction: What role for the state in today's globalised economy?* London: Zed Books Ltd.

Mangcu, X. (2008), *To the Brink: The state of democracy in South Africa*, Pietermaritzburg: University of KwaZulu-Natal Press.

Marshall C. and Rossman G. B. (1995), *Designing Qualitative Research*, London: Sage Publications.

Mbali, M. (2005), "The Treatment Action Campaign and the History of Rights-Based, Patient-Driven Activism in South Africa", in *Centre for Civil Society Publications*, University of KwaZulu-Natal: Durban.

Mbali, M. (2003), "HIV/AIDS policy-making in post-apartheid South Africa," in Daniel, J., *et al*., (eds.) *State of the Nation. South Africa 2003-2004*, Cape Town: HSRC Press.

Medecins Sans Frontieres. (2003), *Strengthening AIDS Care in the Eastern Cape, South Africa: Project Proposal*, Revision April 2003, Lusikisiki.

Medecins Sans Frontieres**.** (2004), *Treating AIDS patients at the heart of the problem,* International Activity Report 2004.

Medecins Sans Frontieres. (2005), *Implementing HIV/AIDS services including ART in a rural resource-poor setting: Siyaphila La program – Lusikisiki, Eastern Cape, South Africa. Activity Report 2003-2004*.

Medecins Sans Frontieres. (2006), *MSF Press Release. Lusikisiki celebrates 2 200 people on ARV treatment at hand-over ceremony*.

MSF and DOH. (2006), *Achieving and Sustaining Universal Access to Antiretrovirals in Rural Areas. The Primary Health Care Approach to HIV Services in Lusikisiki, Eastern Cape.* www.msf.be/fr/pdf/lusikisiki_final_report.pdf. Downloaded 09/12/2011.

Mercer, C. (2002), "NGOs, civil society and democratisation: a critical literature review," in *Progress in Development Studies*, Vol. 2, No. 1, pp. 5-22.

Mercer, M. A., Liskin, L and Scott, S. J. (1991), 'The role of non-governmental organisations in the global response to AIDS', in *AIDS Care*, 3 (3), pp. 265-270.

Mhone, G. and Edigheji, O. (2003), "Globalisation and the Challenge of Governance in the New South Africa: introduction," in Mhone, G & Edigheji, O., (eds.), *Governance in the New South Africa: The Challenges of Globalisation*, Lansdownne: University of Cape Town Press.

Midgal, J. S. (2001), *State in Society: Studying how states and societies transform and constitute one another*, Cambridge: Cambridge University Press.

Millstein, M. (2007), *Challenges to substantive democracy in post-apartheid Cape Town: The politics of urban governance transformations and community organising in Delft*. PhD. Study submitted October 2007, University of Oslo: Department of Sociology & Human Geography.

Mindry, D. (2008), 'Neoliberalism, Activism and HIV/AIDS', in *Social Text 94*, Vol 26, No. 1, Spring 2008, pp. 75-93.

Mintzberg, H. (2010), "Developing Leaders? Developing Countries?", in *Oxford Leadership Journal*, Vol. 1, Issue 2, pp. 1-10.

Moeller, S. (2000), 'Coverage of AIDS in Africa: The media are silent no longer' in *Nieman Reports*, Fall 2000, Vol. 54 (3), pp. 89-94.

Mogale, T. M. (2003), "Developmental Local Government and Decentralised Service Delivery in the Democratic South Africa," in Mhone, G & Edigheji, O. *et al*., (eds.), *Governance in the New South Africa: The Challenges of Globalisation*, Lansdowne: University of Cape Town Press.

Mohan, G. (2002), "The disappointments of civil society: the politics of NGO intervention in northern Ghana", in *Political Geography* 21, pp. 125-15.

Morfit, N. S. (2011), "AIDS is money": how donor preferences reconfigure local realities', *World Development*, 39(1), pp. 64-76.

Moscovici, S. (1961), *La psychoanalyse, son image et son public*, Paris: Press Universitaires de France.

Mosse, D. (2001), "Social research in rural development projects", in D. Gellner and E. Hirsch (eds). *Inside organizations: Anthropologist at work*, Oxford: Berg.

Mosse, D. (2004), "Is Good Policy Unimplementable? Reflections on the Ethnograpghy of Aid Policy and Practice", in *Development and Change 35 (4)*, pp. 639-671.

Mosse, D. (2005), *Cultivating Development: And Ethnography of Aid Policy and Practice*, England, University of London: Pluto Press.

Mosse, D., Farrington, J. and Drew, A. (Eds.) (l998), *Development as a process: Concepts and methods for working with complexity*, London: Overseas Development Institute and New York: Routledge.

Murphy, B. (1991), "Canadian NGOs and the politics of participation", in Swift, J and Tomlinson, B. (eds) *Conflicts of interest*, Toronto: Between the Lines.

M'zamini, B. et al. (2007), "Strengthening community health systems : perceptions and responses to changing community needs," Geneva, Switzerland : Global Fund strategic Information and Evaluation Unit.

Nattrass, N. (2004), *The Moral Economy of AIDS in South Africa*, Cambridge, UK and New York: Cambridge University Press.

Nattrass, N. (2005), "Rolling out antiretroviral treatment in South Africa: economic and ethical challenges", in van Niekerk, A. A and Kopelman, L. M (Eds.), *Ethics & AIDS in Africa: The Challenge to our Thinking*, South Africa: David Philip Publishers.

Nattras, N. (2006), *AIDS, Science and Governance: The battle over Antiretroviral Therapy in Post-apartheid South Africa*, University of Cape Town: Center for Social Science Study.

Nattrass, N. (2007), *Mortal Combat: AIDS denialism and the struggle for antiretrovirals in South Africa*, Pietermaritzburg: University of KwaZulu-Natal Press.

Nauta, W.W. (1999), *The Implications of Freedom: the changing role of land sector NGOs in a transforming South Africa*, Münster: Lit Verlag.

Nauta, W.W. (2001), The Implications of Freedom: the changing role of land sector NGOs in a transforming South Africa, Amsterdam: dissertation de Vrije Universiteit.

Nauta, W.W. (2004), "A Moral Critique of Fieldwork", in O. Salemink, A. van Harskamp and A. Kumar Giri (ed.) *The Development of Religion/the Religion of Development*, Delft: Eburon Press, International distribution: Chicago University Press.

Nauta, W.W. (2012), Democratic Deepening in South Korea and South Africa in an Age of Global Rebalancing: The Potential Role of Civil Society in the Era of Internet, in J. Nederveen, Pieterse and J. Kim (Eds.) *Globalization and Development in East Asia*, New York: Routledge.

Nelkin, D. (1991), 'AIDS and the news Media' in *Milbank Quarterly*, 69 (2), pp. 293-307.

Nelson Mandela Foundation and Medecins Sans Frontieres. (2006), *Achieving and Sustaining Universal Access to Antiretrovirals in Rural Areas: The Primary Health Care Approach to HIV Services in Lusikisiki, Eastern Cape*, MSF: Cape Town.

Nicolson, R. (1995), AIDS*: A Christian Response to HIV/AIDS*, Pietermaritzburg: Cluster Publications.

Nicolson, R. (1996), *God in AIDS? A Theological Enquiry*, London: SCM Press.

NORAD. (1991), *AIDS, new challenges in development cooperation: food for thought* from a NORAD/ NGO workshop on AIDS and development, Oslo, Norway: NORAD.

Ntuli, S. (2003), *Amandla!: A Revolution in Fair-Part Harmony*, Dir. Lee Hirsch, Artisan Entertainment.

Nyamwaya, D. O. (1997), 'Three Critical Issues in Community Health Development Projects in Kenya', in Grillo, R. D. and Stirrat, R. L. (Eds.), *Discourses of Development: Anthropological Perspectives*, Oxford: Berg.

O'Manique, C. (2004), *Neoliberalism and AIDS Crisis in Sub-Saharan Africa: globalisation pandemic*, New York: Palgrave Macmillan.

Overberg, K. R. (Ed.). (1994), *AIDS, Ethics and Religion: Embracing a Suffering World*, Maryknoll, New York: Orbis Books.

Parfitt, T. (2002), *The End of development: Modernity, Post-Modernity and Development,* London: Pluto Press.

Parfitt, T. (2004), 'The ambiguity of participartory development and empowerment: the dangers of localism', in *Third World Quarterly*, 25 (3). Pp. 537-556.

Parker, W. (2000), *HIV/AIDS and the press: experiences in promoting social action*. Paper presented at the XIII international AIDS Conference, Durban, South Africa, 9-14 July 2000.

Parker, W. (2005), *HIV/AIDS, Claims-Making and the Public Sphere: Are We Being Critical Enough about the Epidemic?* Johannesburg, South Africa: Centre for AIDS Development, Study and Education.

Parker, W. and Kelly, K. (2001), *Writing the epidemic: the role of the South African media in shaping responses to HIV/AIDS*. Presentation at the AIDS in Context Conference, University of the Witwatersrand, Johannesburg, South Africa, 4-7 April 2001.

Patterson, A. S. (Ed.). (2005), *The African State and the AIDS Crisis*, England: Ashgate.

Patterson, A. S. and Haven, B. (2005), "AIDS, Democracy and International Donors in Ghana, in Patterson, A. S. (Ed.), *The African State and the AIDS Crisis*, England: Ashgate.

Pearce, J. (1993), 'NGOs and Social Change: agents or facilitators?' in *Development in Practice*, Volume 3, Number 3, October 2003, pp. 222-227.

Peet, R. and Hartwick, E. (1999), *Theories of Development*, New York: Guilford Press.

Peires, J. (1990). "Suicide or genocide: Xhosa perceptions of the Nongqawuse catastrophe", *Radical History Review* Vol. 46, No.7, pp. 47-57.

PEPFAR. (no date), "PEPFAR Funding: How is the Money Spent?" available at www.avert.org/pepfarfunding.htm.

PEPFAR. (no date), The ABC of HIV Prevention," available at www.avert.org/abc-hiv.htm; Foreign Policy in Focus, "The Flawed ABCs of PEPFAR."

Petras, J. and Veltmeyer, H. (2001), *Globalisation Unmasked: Imperialism in the 21st century*, Halifax: Fernwood Publishing.
Pfeffer, J. and Salancik, G. R. (1978), *The External Control of Organisations: A Resource Dependence Perspective*, New York: Hatper & Row.

Pieterse, J. N. (2000), 'After post-development', in *Third World Quarterly*, 21(2), pp. 171-191.

Pierre, J. and Peters, B. G. (2000), *Governance, Politics and the State*, London: MacMillan Press.

Pisani, E. (2008), *The Wisdom of Whores: Bureaucrats, Brothels and the Business of AIDS*, London: Granta.

Pollard, A. B III. (1999), “Rhythms of Resistance,” in Nelson, A. M (Ed.), *This is How we Flow: Rhythm in Black Cultures*, Columbia, SC: University of South Carolina Press.

Porter, G. (2003), NGOs and poverty reduction in a globalizing world: perspectives from Ghana, in *Progress in Development Studies,* 3(2), pp. 131-145.

Postma, W. (1994), 'NGO partnership and institutional development: making it real, making it intentional' *Canadian Journal of African Studies*, *V*ol. 28, no 3.

Power, G., Maury, M. and Maury, S. (2002), “Operationalising bottom-up learning in international NGOs: barriers and alternatives”, in *Development in Practice* 12 (3-4), pp. 272-284.

Purikh, A. and Whiteside, A. (2007), “Twenty-five years of HIV/AIDS: South Africa’s policy challenges”, in *The Fletcher Forum of World Affairs*, Vol. 31: 1 Winter.

Roberts, R. S. (2007), *Fit to Govern: The Native Intelligence of Thabo Mbeki*, Johannesburg: STE Publishers.

Rist, G. (1997), *The History of development: from western Origins to Global Faith*, London and New York: Zed Books.

Robins, S. (2004), “‘Long Live Zackie, Long Live’: AIDS Activism, Science and Citizenship after Apartheid”, in *Journal of Southern African Studies, Vol. 30, No. 3*, September 2004, pp. 655-672.

Robins, S. (2004b). *ARV drugs bring hope to Pondoland*. http://www.healthe.org.za/news/article.php?uid=20030948. Downloaded 21/09/2011

Sabatini, C. A. (2002), ‘Whom do international donors support in the name of civil society?’, in *Development in Practice*, Volume 12, Number 1, pp. 7-19.

Sachs, W. (1992), *The Development Dictionary*, London: Zed Books.

Salamon, Lester M. (1995), *The international guide to non-profit law*, New York: Wiley.

SANCO. (2007), *END AIDS! Break the Chains of Pharmaceutical Colonialism*, South Africa: SANCO and the Dr. Rath Health Foundation Africa.

Schneider, H. and Gilson, L. (1999), ‘Small fish in a big pond? External aid and the health sector in South Africa’, in *Health Policy and Planning, Vol. 14, No. 3*, pp. 264-272.

Schneider, H. (2001), 'The AIDS Impasse in South Africa as a Struggle for Symbolic Power', in *AIDS in Context Conference*, University of Witswatersrand, 2001.

Schoofs, M. (2000), *The media in the message: Acase study in AIDS journalism*, International Conference on AIDS, Durban.

Seckinelgin, H. (2004), 'Who Can Help People With HIV/AIDS in Africa? Governance of HIV/AIDS and Civil Society', in *Voluntas: International Journal of Voluntary and Nonprofit Organizations*, *Vol. 15, No. 3*, pp. 287-304.

Seekings,J. & N. Nattrass (2005), *Class, race and inequality in South Africa,* Yale: Yale University Press.

Simchowitz, B. (2004), *Social security and HIV/AIDS: assessing "disability" in the context of ARV treatment*, CSSR Working Paper No. 99.

Sen, A. (1999), *Development as Freedom*, New York: Anchor Books.

Shepperson, A. (2000), *HIV/AIDS Reporting in South Africa: An analysis of the response of the press*, Johannesburg: CADRE.

Shisana, O. (2006), "How we know there is an HIV epidemic in South Africa", in *EQUAL TREATMENT: Newsletter of the Treatment Action Campaign – The Science of HIV/AIDS*, March 2006.

Shreedhar, J. and Colaco, A. (1996), *Broadening the front: NGO responses to HIV and AIDS in India*, London: Actionaid; New Delhi: British Council: UNDP, United.

Siegal, N. (2004), ''No Experience Necessary: A Profile of Bush's AIDS Czar'', in *Progressive 68*, no. 11, November 2004.

Soeftestad, T. L. (1998), *Population, Economic Development, and Environment: The Making of Our Common Future*, Oxford: Oxfrod University Press.

Shisana, O., et al., (eds.), (2005), *South African National HIV Prevalence, HIV Incidence, Behaviour and Communication Survey*, Cape Town, South Africa: Human Science Study Council.

Shisana, O. (2004), *Gender and HIV/AIDS: focus on Southern Africa*, Paper delivered at the inaugural International Institute on Gender and HIV/AIDS, 7th of June 2004, South Africa.

Slater, D. (1993), "The Geopolitical Imagination and the Enframing of Development Theory", in *Transactions of the IBG*.

Smillie, I. (1994), "Changing partners: Northern NGOs, Northern governments", in *Voluntas* vol 5, no 2, pp. 155-192.

State of the Union. (2003), available at: www.whitehouse.gov/news/releases/2003/01/20030128-19.html.

Stein, J. (2001), *HIV/AIDS and the Media: A Literature Review*, Johannesburg: Centre for AIDS Development Study and Evaluation.

Stein, J. (2003), "What's News: Perspectives on HIV/AIDS Advocacy in the South African Media," Center for Social Science Study, *Working Paper No. 37*.

Steinberg, J. (2008), *THREE~LETTER PLAGUE: Ayoung man's journet through a great epidemic*, Johannesburg & Cape Town: Jonathan Ball Publishers.

Stillwagon, E. (2001), 'Aids and poverty in Africa', in *The Nation,* 21st May 2001.

Stirrat. R. L. and Henkel, H. (1997), The Development Gift: The Problem of Reciprocity in the NGO World. Annals of the American Academy of Political and Social Science, Vol. 554, *The Role of NGOs: Charity and Empowerment*, Nov., 1997, pp. 66-80.

Strand, P. et al. (2005), *HIV/AIDS and Democratic Governance in South Africa. Illustrating the Impact on the Electoral Processes*, Pretoria: Institute for Democracy in South Africa (IDASA).

Strode, A. et al. (2004), *Understanding the institutional dynamics of South Africa's Response to the HIV/AIDS pandemic*, Cape Town: Idasa.

TAC. (2003), *Report for January 2002-February 2003*. Accessed at: http://www.tac.org.za/Documents/report02to03pdf. 2003.

TAC. (2005), Minutes of the NEC meeting 24-25 January 2005, Retrieved from http://www.tac.org.za

TAC. (2005), *Evaluation*, 29 June 2005.

TAC (2006), *ARV drugs in our lives. A handbook for people living with HIV and treatment*
*advocates in support groups, clinics and communities.*
http://www.tac.org.za/documents/ARV drugsinourlives.pdf. Downloaded 10/11/2012

Tandon, R. (1990), 'Partnership in social development evaluation: a thematic paper' pp96-113 in Marsden, D, and Oakley, P. (ed.) *Evaluating social development Projects*, Oxford: Oxfam.

The Henry J. Kaiser Family Foundation. (2008), "President Bush Signs PEPFAR Reauthorization Bill", available at www.kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=53609.

Treichler, P. (1999), *How to have a theory in an epidemic Cultural chronicles on AIDS*, London: Duke University Press.

Turner, B. S. (2000), *A Companion to Social Theory*, Malden: Blackwell Publishers Ltd.

Turner, M. and Hulme, D. (1997), *Governance, Administration and Development. Making the State Work,* New York: Palgrave.

Ullestad, N. (1987), "Rock and Rebellion: Subversive Effects of Live and 'Sun City'," in *Popular Music, Vol. 6, No. 1*, 1987, pp67-76.

UNAIDS. (2004), The 'Three ones': Driving concerted action on AIDS at country level, Geneva: UNAIDS.

UNAIDS. (2006), *Report on the Global AIDS Pandemic.* <www.unaids.org/en/HIVdata/ 2006GlobalReport/default.asp> (accessed October, 26 2006).

UNAIDS (2006). Report on the global AIDS*. HIV/AIDS estimates and data;* Geneva: UNAIDS Publications.

UNAIDS. (2006), *South Africa.* http://www.unaids.org/en/Regions_Countries/Countries/south_africa.asp. Downloaded 11/08/2011

UNAIDS and The Henry J. Kaiser Foundation. (2011), "Financing the response to AIDS in Low- and Middle-income Countries: International Assistance from the G8, European Commission and Other Donor Governments in 2010", July 2011.

UNAIDS. (2012), "Global Report: UNAIDS Report on the Global AIDS Epidemic 2012.

UNCCD. (2005), *Revitalizing Traditional Knowledge. A Compilation of Documents and Reports from 1997-2003*, Germany Bonn: UNCCD.

UNDP. (2004), "AIDS and failed Development" in http://www.africaaction.org/docs0/rau0010.htm accessed on 18 August 2004.

UNDP. (2006), *Country Report 2006*.

United Nations Environment Programme (UNEP). (1992), *Convevtion on Biological Diversirty*, NairobiL UNEP.

U.N. Integrated Regional Information Networks. (2009), "A new and improved PEPFAR under Obama?" available at www.irinnews.org/report.aspx?ReportID=82494

USAID. (1997), "New partnership initiative (NPI) resource guide: a strategic guide to development partnering", Report of the NPI Learning Team, Washington DC: United States Agency for International Development.

U.S Embassy. (2006), Kampala, Uganda, "US AIDS Coordinator Ambassador Eric Goosby visits Uganda", available at kampala.usembassy.gov/ambassador_goosby.html.

Vail, L. and White, L. (1991), *Power and the Praise Poem: Southern African Voices in History*, Charlottesville: The University Press of Virginia.

Van der Vliet, V. (2004), "South Africa Divided against AIDS: A Crisis of Leadership", in Kauffmann, K. and Lindauer, D. (Eds.) *AIDS and South Africa: The Social Expression of a Pandemic,* New York: Macmillan, pp. 48-96.

Vinson, R. (2012), *The Americans Are Coming; dreams of African American Liberation in Segregationist South Africa*, Ohio University Press: Ohio.

Walker, R. (1985), *Applied Qualitative Research*. Aldershot: Gower.

Wallace, T., Crowther, S. and Shepherd, A. (1997), *Standardising Development: Influences of UK NGOs' policies and procedures*, Oxford: Worldview Press.

Wallace, T., Bornstein, L and Chapman, J. (2006), *Coercion and Commitment: NGOs in the aid chain*, London: ITDG.

Wallace, T. and Chapman, J. (2004), 'An Investigation into the Reality behind NGO Rhetoric of Downward Accountability', in Lucy Earle (ed.) *Creativity and Constraint: Grassroots Monitoring and Evaluation and the International Aid Arena*, London: Intrac.

Whiteside, A. (2004), “HIV/AIDS, Poverty and Development,” from http://www.odi.org.uk/booth.html, accessed on 26 August 2004.

Whiteside, A. and Sunter, C. (2000), *AIDS: The Challenge for South Africa,* Human & Rousseau Tafelberg Publishers.

Wilson, G. (2007), “Knowledge, innovation and reinventing technical assistance for development”,in *Progress in Development Studies* 7(3), pp. 183-199.

WHO. (2005a), *‘3 by 5’ Progress Report*. Geneva: World Health Organisation and UNAIDS.

WHO. (2005b), *Progress on Global Access to HIV Antiretroviral Therapy: An Update on ‘3 by 5’*. Geneva: World Health Organisation and UNIADS.

WHO/UNAIDS/UNICEF, 2011 ,'Global HIV/AIDS Response: Epidemic update and health sector progress towards Universal Access 2011'

Wiley, D. (2001), *Starving on a Full Stomach: hunger and Triumph of Cultural Racism in Modern South Africa*, University Virginia Press: Charlottesville.

World Bank. (1995), *Working with NGOs: A Practical Guide to Operational Collaboration between the World Bank and Non-Governmental Organisations*, Washington DC: Operations Policy Department.

World Bank. (2006a), *World Bank-Civil Society Engagement: Review of Fiscal Years 2005 and 2006*, Washington DC: Civil Society Team.

Yanacopulos, H. (2005), ‘The Strategies that Bind: NGO Coalitions and Their Influence’, in *Global Networks*, 5 (1), pp. 93-110.

---------- (April 2006), United States Government Accountability Office (GAO), Global Health Spending Requirement Presents Challenges for Allocating Prevention Funding under the President’s Plan for AIDS Relief, GAO-06-395.

---------- (2003), “President Discusses the Fight Against Global and Domestic HIV/AIDS,’’ January 31, 2003; available at www.whitehouse.gov/news/releases/2003/01/20030131-4.html.

**Interviews**

| | |
|---|---|
| Interview with Booi, Ntombekhaya, Lusikisiki | March 2007 |
| Interview with Booi, Zimkitha, Lusikisiki | August 2006 |
| Interview with Community member, Lusikisiki | February 2008 |
| Interview with Court, Kathy, Grahamstown, | March 2007 |
| Interview with Dunjwa, Pinky Lusikisiki | March 2007 |
| Interview with Gqamane, Nombeko. Lusikisiki | November 2006 |

Interview with Gqamane, Nombeko. Lusikisiki February 2007
Interview with Gxunuwe, Nombasa. East London October 2006
Interview with Hanesi, Ntombi, Lusikisiki March 2007
Interview with Hesjedal, Siv. East London, January 2007
Interview with Jouquet, Guillaume. Lusikisiki, August 2006
Interview with Jouquet, Guillaume. Lusikisiki October 2006
Interview with Jwara, Neliswa Lusikisiki March 2007
Interview with Jwara, Nosipelo, East London April 2008
Interview with Kelias, Emmanuel, East London March 2007
Interview with Kutu, Mbulelo, King William's Town June 2007
Interview with Ludidi, Nopiwe. East London, May 2006
Interview with Mabhena, Siphokazi Lusikisiki November 2008
Interview with Mkani, Phindi, Lusikisiki March 2007
Interview with Makubalo, Ntombenkosi. Lusikisiki November 2006
Interview with Manana, Asekho, Lusikisiki March 2007
Interview with Maila, Nolitha. Lusikisiki, November 2006
Interview with Matika, Patisa, Lusikisiki March 2007
Interview with Matutu, Bongeka Libode March 2007
Interview with Matutu, Bongeka Libode February 2009
Interview with Mbona, Nqabakazi. Mdantsane, January 2007
Interview with Menyo, Vukani, Lusikisiki August 2007
Interview with Mjoji, Nosizwe. Lusikisiki, November 2006
Interview with Mjoji, Nosizwe, Lusikisiki November 2007
Interview with Mjoji, Nosizwe, Lusikisiki November 2008
Interview with Mokoena, Philip. East London July 2006
Interview with Mokoena, Philip. East London November 2006
Interview with Mokoena, Philip. Durban March 2007
Interview with Mokoena, Philip. East London October 2007
Interview with Moloto, Jonasi, Lusikisiki March 2007
Interview with Motabene, Zimbini, Lusikisiki March 2007
Interview with Mkumbuzi, Zanele Lusikisiki February 2009
Interview with Mthembu, Thobile Lusikisiki March 2007
Interview with Ndola, Thabo, East London March 2007
Interview with Neli, Zinzi, Lusikisiki March 2007
Interview with Ngcongolo, Bulelwa, Lusikisiki November 2007
Interview with Ngcaba, Portia, East London April 2008
Interview with Nitini, Dumza, Lusikisiki August 2006
Informal conversation with Ntini, Solomzi. Libode August 2006
Interview with Ntamehlo, Noloyiso, Lusikisiki November 2006
Interview with Ntamehlo, Noloyiso, Lusikisiki November 2007
Interview with Ntamehlo, Noloyiso, Lusikisiki November 2008
Interview with Ntantala, Simpiwe, Lusikisiki November 2008
Interview with Nosiphelo Mfeketo, Lusikisiki March 2007
Interview with Nqini, Thobile, Bisho March 2007
Interview with Ntsabula, Akona. Lusikisiki November 2006
Interview with Reuter, Hermann. Lusikisiki August 2006

Interview with Reuter, Hermann. Lusikisiki October 2006
Interview with Shushu, Nomapondomise, Lusikisiki November 2008
Interview with Van Niekerk, Jabu, Grahamstown March 2007
Interview with Vumbani, Bavuyise, Lusikisiki November 2007
Interview with Vimbani, Bavuyise, Lusikisiki November 2008
Interview with Vimbani, Bavuyise, Lusikisiki February 2009
Interview with Vinjwa, Thandeka. Lusikisiki November 2006
Interview with Vinjwa, Thandeka. Lusikisiki November 2007

**Newspaper Articles**

*Business Day*, 25 August 2006, 'Only failure of AIDS plan is in communication – State: "Perception that government does care is false."
*Business Day*, 30 October 2006, "Learning the lessons of Lusikisiki."
*Daily Dispatch*, 4 December 2001,"Manuel questions AZT effect."
*Daily Dispatch*, 26 March 2002, "Staffing problems at CHM's Aids site says TAC."
*Daily Dispatch*, 25 April 2002, "TAC asks EC govt to provide Aids drug."
*Daily Dispatch*, 4 December 2002, "TAC condemns delay in giving anti-retrovirals."
*Daily Dispatch*, 15 July 2005, "Transkei areas 'setting pace' for ARV rollout."
*Daily Dispatch*, 2 November 2005, "Lusikisiki Leads the ARV way."
*Daily Dispatch*, 8 October 2006, "Bisho bungles Aids scheme."
*Daily Dispatch*, 1 February 2007, "New horror Aids statistics for EC."
*Daily Dispatch*, "20 000 learners set to take part in TAC Bisho march."
*Daily Dispatch*, "Fire Manto, says De Lille, TAC and PAC."
*Daily Dispatch*, "E Cape health dept denies Aids treatment bungle."
*Daily Dispatch*, 5 January 2008, "Sacking of Cabinet's HIV fighter 'an insult.'"
*Daily News*, 27 August 2007, "TAC launches fund for axed minister."
*International Herald Tribune*, August 9 2007, "Mbeki fires aide who reshaped HIV policy."
*Mail & Guardian Online*, 30 January 2007, "Aids rises among South Africa's rich, say studyers."
*Mail & Guardian*, August 11 2007, "President breaks silence on Nozizwe";
*Mail & Guardian*, August 14 2007, "Mbeki vulnerable after sacking Nozizwe."
*New York Times*, 14 August 2007, "Firing an AIDS Fighter."
*Sunday Times*, 20 August 2006, "Time to sack Health Minister."
*Sunday Tribune*, 27 August 2006, "How can we cure Manto."
*The Independent World*, August 13 2007, "Mbeki says minister was sacked for insubordination."
*Washington Post*, 6 July 2000, "Death Watch: South Africa's Advances Jeopardized by Aids."
______, "Good food no substitute for ARV drugs – Scientists."
______, "Liver transplant for Health Minister."

**Speeches**

Achmat, Z. *Kamera: Leva med HIV*. (SVTV 2, July 9th 2002).

**Treatment Action Campaign Gatherings & Rallies**

| | |
|---|---|
| Public Hearing, Lusikisiki | 25-27 November 2007 |
| Public Hearing, Lusikisiki | December 2008 |
| Protest March Against Rath Foundation, Cecilia Makiwane Hospital, 27 October 2007 | |
| World AIDS Day, East London | December 2007 |
| World AIDS Day, Lusikisiki | December 2008 |

**Websites**

http://www.doh.gov.za/docs/index.html.
http://www.mg.co.za.
http://www,tac.org.za.
http://www.aids.org.za/hiv.htm.
http://www.undp.org/hiv/index.html.
http://www.info.gov.za/otherdocs/2003/aidsoperationalplan/pdf.
http://www.info.gov.za/speeches/2003/03111916531001.htm.
http://www.health-e.org.za/news/article.php?uid=20031298.
http://www.thenation.com/doc.mhtml?i?20010521&s=stillwaggon.
http://www.icrn.org.
http://www.africaaction.org/docs0/rau0010.htm.
http://www.worldbank.org/aids-econ/aids.html.
http://www.odi.org.uk/booth.html.