UNITED AGAINST HIV/AIDS?

The politics of local governance in the case of Lusikisiki South Africa

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Master Thesis in Human Geography
Department of Sociology and Human Geography
University of Oslo, 2007

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List of Abbreviations

AIDS	Aquired Immuno Deficiency Syndrome
ANC	African National Congress
ART	Anti Retro viral Treatment
ARV	Anti Retro Virals
CBO	Community Based Organisation
CSO	Civil Society Organisation
DoH	Department of Health
EC	Eastern Cape
HAACO	HIV/AIDS Adherence Counsellors Organisation
HAST	HIV/AIDS, STIs and TB committee
HIV	Human Immunodeficiency Virus
MSF	Médecins Sans Frontières
MTCT	Mother To Child Transmission (of HIV)
NACOSA	National Aids Convention of South Africa
NGO	Non-Governmental Organisation
NMF	Nelson Mandela Foundation
NSP	National Strategic Plan
PLWHA	People Living With HIV/AIDS
PMTCT	Prevention of Mother To Child Transmission (of HIV)
SANAC	South African National AIDS Council
TAC	Treatment Action Campaign
TB	Tuberculosis
UNAIDS	The Joint United Nations Programme on HIV/AIDS
VCT	Voluntary Counselling and Testing

Map of South Africa locating Lusikisiki

Source: MSF and NMF 2006:6

Photos: By author.

1. INTRODUCTION

The objective of this thesis is to study the politics of governance of HIV/AIDS[1] treatment at a local level in South Africa. During the last two decades, the country has experienced a shift from debates around the politics to the governance of treatment for HIV/AIDS. The question of what ought to be government policy regarding HIV/AIDS is an area that sparked debates and conflicts between state and civil society actors. It is also an area that has received much attention from academic circles and media both at a national and international level. This was the area of interest that motivated the choice of topic for my study. Now that South Africa is moving from debates over policy towards the actual implementation of such, how do you ensure a smooth transition including multiple actors in the process? How can new policies on treatment for HIV/AIDS be successfully implemented at a local level ensuring the participation of multiple actors both from the state and the civil society organisations?

The case of study in this thesis is the Lusikisiki HIV/AIDS programme. This study is interesting not only because it is one of the first (rural) treatment programmes in South Africa, but despite the conflicts between the state and civil society over HIV/AIDS policies, this is a case where the two central actors representing each side, the Department of Health and the Treatment Action Campaign, seemed to have put aside their previous conflicts and engaged in local treatment collaboration together with the international NGO Médecins Sans Frontières. Then what are the consequences when the external actor pulls out?

Research questions

An underlying presumption informing the choice of topic for this thesis is that due to the history of conflicts over HIV/AIDS policies in the South African context (which will be elaborated on below), it will be challenging to engage in collaboration and partnerships between state and civil society actors to ensure the roll-out of Anti-Retro Viral (ARV)[2] treatment. However, it is not my intention to examine the overall nature and character of state-civil society treatment collaborations in South Africa. I rather attempt to shed light on the dynamics operating in a context of local governance of HIV/AIDS; the case of the Lusikisiki

[1] HIV stands for Human Immunodeficiency Virus. AIDS is short for Aquired Immuno Deficiency Syndrome.
[2] Anti-Retro Virals (ARVs) is a generic term for HIV/AIDS treatment.

HIV/AIDS programme. Hence the research questions that have guided me through this study are:

- *What characterises the partnerships and collaboration in the Lusikisiki programme? And what are the main challenges to the cooperation?*

- *What was the role played by civil society actors and how did this affect the programme and collaboration?*

- *What are the implications of making the NGO-driven pilot into a government run programme?*

In answering these research questions, I do not intend to study the national roll out of treatment as such, but rather examine a local case where a treatment roll out has been implemented since 2003. Though shedding light on a case in which such collaboration has been implemented, I also attempt to illustrate how the local case is connected to a broader context of national governance of HIV/AIDS in the concluding chapter. Furthermore, my study is limited to three central actors involved in rolling out HIV/AIDS treatment in Lusikisiki: Médecins Sans Frontières, the Department of Health and the Treatment Action Campaign.

In order to give a background for the research questions this thesis is founded on, there is firstly a need to take a closer look at the history of South African politics around HIV/AIDS treatment. It should be kept in mind that in order to understand the partnerships and relations between state and civil society actors in Lusikisiki, there is a need to take account of the history and historical relations between state and civil society in the context of HIV/AIDS prior to the implementation of the Lusikisiki programme. On a national level, there has been a conflict between the part of civil society mobilising for the rights to and roll-out of ARVs, led by TAC and its allies, and the government's neglect for such demands. This conflict has to a certain extent trickled down to the provincial as well as the local level, as will be seen in the chapters of the analysis. Secondly, I will give a presentation of the case of study in this thesis; the Lusikisiki HIV/AIDS programme.

The politics of HIV/AIDS treatment in South Africa

When the former leaders of the anti-apartheid movement became the new political leadership of the country, many believed that 'the adversarial social struggle' with the state had ended. However, within a few years of democracy, new social struggles emerged between the state and civil society. An example of the new struggles that emerged came due to increasing discontent regarding the government's lack of effective HIV/AIDS action, led by the Treatment Action Campaign (TAC) (Ballard et al. 2006).

South Africa has an estimated HIV-prevalence of 18.8% (referring to adults aged 15-49) and about 5.5 million people are living with HIV/AIDS in South Africa (UNAIDS 2006). Without ARVs, a newly HIV infected person will meet a certain death within 4-15 years (Fourie 2006).

The politicisation of HIV/AIDS in South Africa did not really arrive until 1992 when the ANC came together with the apartheid government's Department of Health in a conference known as "South Africa United Against Aids". It resulted in the formation of the National Aids Convention of South Africa (NACOSA), which gathered a number of important multi-sectoral actors such as political parties, trade unions, NGOs, religious institutions and health workers (Fourie 2006, Van der Vliet 2004).

The post-apartheid governments have been receiving fierce criticism both at a national and international level for their lack of leadership in battling the epidemic. President Mbeki was set to lead the response against HIV and AIDS when he entered the presidential office in 1998. Only two years later, he was setting up a presidential panel with high-profiled dissidents, which became an arena for discussing the causes of AIDS (Fourie 2006, Mbali 2003, Van der Vliet 2004).

Mbeki and other state leaders have repeatedly questioned the link between HIV and AIDS and employed an approach to the epidemic which has been labelled 'AIDS denialism' (Mbali 2003, Nattrass 2004, Jones 2004c, Van der Vliet 2006). South African state leaders' flirtation with controversial views regarding the causal links between HIV and AIDS had a braking

effect on national policies and affected the legitimacy of policies emanating from the people in power (Van der Vliet 2004).

The multisectoralism that NACOSA envisioned vanished with the establishment of the South African National Aids Council (SANAC) in 2000. It was a council consisting of 15 cabinet members, each with little prerequisites to be representatives in such a setting. Simultaneously, civil Society Organisations (CSOs) have been more or less excluded from national governance structures on HIV/AIDS and even structures intended to multi-sectoral such as the National AIDS Council, have given very little space for civil society involvement (Jones 2004c, Van der Vliet 2004). Yet civil society involvement and multisectoralism are seen as crucial in fighting the epidemic (Jones 2004c, Nattrass 2004).

Jones (2004c:8) argues that "there is no more powerful evocation of the acute disjuncture between civil society and the state in South Africa than that concerning policy on HIV/AIDS". The government and civil society actors have taken radically different approaches to what such government policies ought to be. Many organisations working in the field have been feeling marginalised in the planning and implementation process regarding HIV/AIDS. The process has been coloured by lack of participation, accountability and transparency, thus gradually breaking down the solidarity and cooperation that coloured the original vision of a "South Africa United Against Aids" (Mbali 2003, Van der Vliet 2004).

A leading civil society organisation advocating for the right to treatment for People Living With HIV/AIDS (PLWHA) is the Treatment Action Campaign (TAC) established in 1998. They have become known internationally as a movement engaged in a struggle against government for the rights to treatment for HIV/AIDS (Mbali 2003, Van der Vliet 2004). Yet their campaigns for the roll out of ARVs in the public sector, has not prevented TAC and government from cooperating on some terms. When more than 40 multinational pharmaceutical companies attempted to take the government to court to avoid the realisation of a legislation opening up for the production of generic drugs and importation of such, TAC mobilised, demonstrated and advocated both at a national and international level in support for the government's legislation. Hence the court case was dropped in 2001 (Mbali 2003).

However, cooperation quickly shifted to conflict. In 2001, TAC felt they could no longer await a roll-out of Prevention of Mother To Child Transmission (PMTCT) programmes.

Together with allies they took the minister of health and most of the provincial ministers of health to the courts to force the government to commit to a strict time frame for rolling out such a programme including the use of the ARV-drug nevirapine. It ended up in the Constitutional Courts where government was made obliged to roll out a national PMTCT programme (Nattrass 2004, Van der Vliet 2004).

Nevertheless, the government continued to neglect a universal roll-out of treatment for people living with HIV/AIDS. The roll-out of ARVs was dismissed by the President and the Minister of Health on grounds of for instance affordability and toxicity of the drugs. In March 2003, TAC decided to launch a civil disobedience campaign due to the government's lack of action. This resulted in mass marches followed up by arrests throughout the country. The campaign was later called off when the then Deputy President asked TAC to give the government more time to respond to demands (Nattrass 2006).

Hence after several years characterised by 'AIDS denialism' amongst South African leaders and conflict between the state, scientists, academics and civil society organisations working for the right to ARVs (Van der Vliet 2004), the political climate changed. A few months after the civil disobedience campaign of 2003, the government launched the long awaited HIV/AIDS operational plan, and they finally seemed committed to start the roll-out of treatment and care across the country (Natrass 2006, TAC 2004). Unfortunately, the Health Minister's persistent statements about the side-effects of ARVs, coupled with calls for the use of garlic, lemon and beetroot to prevent transmission of HIV, has contributed to confusing messages around treatment for HIV/AIDS in South Africa. It thus adds an additional burden to health personnel and success of treatment programmes on dispelling the myths of 'poisonousness' causing people to refrain from taking ARVs (Nattrass 2006). It was in this context of a changing but still challenging climate that the case of study in this thesis came into existence.

The case of the Lusikisiki HIV/AIDS programme

Médecins Sans Frontières (MSF) started its first HIV/AIDS programme in South Africa, the Khayelitsha programme, in Cape Town 2000. It was a collaboration with the Provincial Administration of the Western Cape which started providing ARVs in 2001, at a time when

provision of these drugs was still considered illegal in the public sector (MSF 2005, MSF and NMF 2006b). It was however an urban programme and MSF wanted to pilot a programme based on the Khayelitsha experiences in a rural area. Hence changes had to be made in order to make it accessible to a poor and dispersed population in more resource-constrained areas than that of Khayelitsha.

The area chosen was Lusikisiki. It is one of the most impoverished and rural areas in the country located in the former 'Transkei', a so-called 'homeland' during apartheid which is now a part of the OR Tambo District in the Eastern Cape Province (MSF and DoH 2006). The provincial Department of Health is suffering from a seriously under-resourced budget (Robins 2004b), something that has unavoidably affected the HIV/AIDS projects in the region. It is estimated that about 24% of the adult population (15-49 years) in the area are HIV-infected (MSF and DoH 2006).

The Lusikisiki HIV/AIDS programme was initiated in late 2002 as a collaboration between Medecins Sans Frontieres (MSF), the Department of Health (DoH) and the Treatment Action Campaign (TAC), with financial support from the Nelson Mandela Foundation (NMF). It was one of the first HIV/AIDS programmes in South Africa providing ARV treatment in a rural area and based upon principles of *decentralised health care*, *task shifting* and *community mobilisation and involvement*.

The decentralisation of the treatment programme to primary health care clinics made it more accessible for a rural population with long distances to travel to the area's only hospital. 12 primary health care clinics around Lusikisiki were chosen as the arena for the programme. Through decentralising HIV/AIDS treatment and care to the clinic level, the programme avoids the enrolment bottleneck often seen in hospitals whilst integrating primary health care and ARV treatment (MSF and NMF 2006, MSF and DoH 2006).

As there were no doctors in the clinics, a strategy of task shifting had to be implemented enabling nurses to initiate and manage ARV treatment. As the nurses were already facing a heavy workload due to 40-50% of nurses' positions being vacant, community members were mobilised and trained to perform many of the former nurses' tasks. Trained adherence counsellors, community care givers and support groups take off much of the workload from the nurses. The MSF training and employment of adherence counsellors is likely to be the

reason why only 2% of patients on ARVs were lost to follow-ups in a year, in comparison to 19% of patients at the hospital. Simultaneously, a mobile medical team with a doctor was established to deal with the overall supervision and issues facing the clinics (MSF and NMF 2006, MSF and DoH 2006). The typical rural bottleneck of lack of skilled health personnel has thus been solved through implementing a strategy of task shifting, community mobilisation and involvement.

The Lusikisiki programme experienced an 18 months gradual handover of responsibilities and management. Whilst as MSF was managing the programme for the first years, the DoH formally took over the management of the programme in a public ceremony in November 2006, and MSF pulled out of the area (MSF 2006, MSF and DoH 2006). In other words, the programme has recently experienced a transition from being a NGO pilot to a government run programme. This has created a number of challenges for the programme. For instance, Lusikisiki experienced a loss of both technical and financial support and bottlenecks to sustaining the original model have been created at the policy level. Spaces and opportunities that were opened up by the external actor have now to a certain extent been closed again.

Structure of the thesis

In order to answer the research questions, this study has employed the use of governance theories and a qualitative case study approach. Hence the two coming chapters outline the theoretical and methodological framework employed in this study.

The next chapter, *the concept and politics of (local) governance*, is the theoretical framework of this thesis. It discusses why it is important to study governance in a context of HIV/AIDS and emphasises the need to study governance politically. It argues that there are numerous actors involved in the politics of governance and discusses implications related to partnerships and participatory governance as well as the role of donors and NGOs. Furthermore, theoretical arguments about the politics of governance are supplemented with Migdal's theory of state-in-society.

The third chapter, *power, politics and ethics: doing research in the context of HIV/AIDS in South Africa*, outlines the methodological considerations this thesis is founded on. It discusses

the choices of methods and sources. It also explains the challenges to doing research related to HIV/AIDS in South Africa and how it affects the collection of data. Central to this chapter are the ethical considerations related to doing research on a topic which can be considered both highly politicised and affected by stigma and emotions. The context in which the research took place and the limitations it created for the collection of data is furthermore an explanatory factor for the findings presented in the analysis.

The fourth, fifth and sixth chapter constitutes the analysis of this thesis. They follow in a 'chronological' order from looking at the initiation of the programme and engagement in partnerships, to the mobilisation of the communities, and finally the recent transition when the Lusikisiki programme became a public sector programme for HIV/AIDS. The backdrop of the three chapters is the research questions as outlined above. Hence the analysis will be working its way through the three research questions in a chronological order.

Chapter four, *from the politics to the governance of treatment*, is connected to the first research questions and related to the partnerships and challenges to cooperation. The challenges to cooperation will be shed further light on also throughout the analysis chapters. This chapter regards a shift from focus on the politics towards the governance of treatment with ARVs. After a change in national policies on treatment, various actors engaged in partnerships to roll out such treatment in Lusikisiki. However they have encountered a range of difficulties. The challenges related to governance of the programme gave TAC a central role as a pressure component ensuring successful implementation and governance of the programme. Their role is thus the focus of chapter five.

Hence chapter five, *social mobilisation and the dual face of Treatment Action Campaign*, shapes the answer to the second research question through examining the role of social mobilisation in the programme, where TAC has played the leading role. The dual face of TAC implies that they have not solely performed a service-delivery role in the programme, but also made use of activism and employed a political and rights-based approach to the mobilisation of the community.

Chapter six, *the politics of transition: from NGO pilot to government run programme*, lays the foundation for answering the last of the three research questions through looking at the impacts of MSF and challenges related to their departure. The chapter investigates their

impact on policy making and implementation, participatory governance and civil society actors. Furthermore, it looks at the consequences of their withdrawal for the programme and the remaining partners.

The *conclusion* ties the previous chapters together and answers the research questions. Secondly, it is argued that the Lusikisiki programme has been characterised by cooperation and conflict both between and within the partners. It is argued that all three partners have what I refer to as ‘dual faces’ and are driven by more than an aim to roll out treatment for HIV/AIDS in Lusikisiki. Furthermore, I argue that despite the programme being physically confined to a small and rural corner of the country, it is nevertheless interconnected with politics of scale and part of a larger question and struggle over defining and implementing the appropriate policies for rolling out HIV/AIDS treatment in South Africa.

2. THE CONCEPT AND POLITICS OF (LOCAL) GOVERNANCE

The Lusikisiki HIV/AIDS programme can be considered a local governance process, where a range of actors both within the state and civil society have engaged in partnerships to ensure the implementation and management of the programme. This thus led me to the employment of a theoretical framework concerned with governance, in general, and in particular the politics of governance.

In this chapter I will start with looking at the concept of 'governance'. This is followed by a discussion of why it can be useful to employ such a theoretical framework when doing research in the context of HIV/AIDS. I then move onto discussions about 'the politics of (local) governance' as illustrated through partnerships and the notion of participatory governance. I will introduce Migdal's theory of 'state-in-society' followed by a conceptualisation of 'civil society'. This is extended by a discussion locating the role of NGOs in governance and how donor-recipient relations impact on governance and aid. In summary, the argument of the chapter regards the relevance of the concept of governance for a study of a local programme for HIV/AIDS treatment, but also the need to understand governance as a matter of power and politics.

The concept of 'governance'

There is no universally accepted and agreed definition of governance. The term 'governance' is frequently being used by social scientists all over the world, however, it is conceptualised in various ways. It has become an umbrella concept that is in many ways vague and comprises theories and approaches which are sometimes even mutually contradictive (Pierre and Peters 2000, Turner and Hulme 1997). Hence, there is a need to briefly present a discussion as to what the concept comprises. What do we mean by 'governance'?

It is acknowledged that 'governance' is a concept concerned with systems of steering and coordination. The disagreement is over *who* is steering or to what extent the various actors are steering. Pierre and Peters (2000) are concerned with governments' role and capacity to steer society through policy making and implementation. They call for a departure with the traditional way of looking at government's role in society. Rather, they argue, there is a need

to study the public sector as something that is not independent and separate from the private sector. The boundaries between the two spheres (public and private) have been blurred as they are increasingly becoming intertwined in various ways. Assumptions about a hierarchical structure of governance with government prevailing on the top, controlling and regulating private sector activities, are not necessarily valid. Today, governments' capacity to steer society is being constrained by participatory mechanisms in governance systems (Pierre and Peters 2000).

Governance approaches

Pierre and Peters (2000) identify two common approaches to looking at governance, as *structure* or as *process.* The latter is based on a more dynamic view of governance, as a natural outcome of the interaction between actors from the political and the social sphere. The structuralist approach to governance, on the other hand, can be further divided into four common governance arrangements; governance as *hierarchies*, as *networks,* as *markets* and as *communities*.

Governance as 'structure'

Where governance is seen as *hierarchies*, the state is separate and independent from society. The state governs society through vertically integrated state structures with the central state on top and sub-national governments below. Government is the only real actor in governance exercising authority through law and in some cases coercion. Simultaneously, some consider governments as governing society with policy instruments. Governance is the result of the choice (and availability) of such instruments. The choice of policy instruments depends on the policy actor and arena. A lawyer is for instance likely to choose a regulatory instrument. In this view, governance is about the capacity of governments to make and implement policies. However, it is misleading to assume that all instruments are available to use for governments (Pierre and Peters 2000).

Most governance literature rejects the hierarchical governance arrangement today as western societies are increasingly being driven by horizontal rather than hierarchical relations, seen through the roles played by networks and other powerful coalitions shaping governance. Hence, the second governance arrangement is looking at *networks* as governance mechanisms. Such perspectives on steering have rather been based on the government's inability to steer independently. Networks may consist of small interest groups or groups

working for larger collective interests. States can also use networks as means to engage societal actors into the policy-process. Policy networks comprises both public and private actors whom together are capable of challenging state powers within their policy sector 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 2000:20). State changes in policies are thus seen as a result of the role of networks. However, the state is still made accountable to policies by its citizens. In other words, the control of governance falls with the networks but the responsibilities are left with the state.

The latter perspectives are divided between those arguing that non-governmental actors have become the central actors in governance and those believing that governments still steer society, though from a distance. Hence, government may still influence on governance, though it has no direct role in steering society. Some argue that despite the increasing importance of horizontal relations in governance arrangements, hierarchical relations still define the relationships between institutions and actors today (Pierre and Peters 2000).

The third governance arrangement weighs *markets* as the central mechanisms of governance. In such an arrangement, citizens gain control over public services as they participate in governance through exercising power as consumers. However, the market arrangement reduces governance to only be driven by economic actors and interests (Pierre and Peters 2000).

A fourth arrangement considers *communities* as governance mechanisms. In this scenario, communities consider themselves more capable of finding solutions to their problems and organising local activities than what the government is. Neither the state nor the market is seen as appropriate governance mechanisms. Communitarian governance is built on community participation and consensus, reflecting the larger collective interests of a community. Yet, the arrangement fails to take into account the potential impact on governance by powerful individuals in the community (Pierre and Peters 2000).

Governance as' process'

Rather than focusing on structures (hierarchies, network, markets and communities), the approach to governance can also be seen as the interaction among the structures; what is referred to as governance as *process*. Governance is then considered to be the result of the

dynamics operating between actors in the political and social sphere. This approach to looking at governance is important as "governance is not so much about structure, but more about interactions among structures" (Pierre and Peters 2000:22). Governance can be considered 'dynamic' as the actors that are involved in governance are likely to vary across time and space. It is thus important to take into account the context in which the various actors are operating.

The governance point of departure

As mentioned above, governance is in much of the literature seen as a 'steering' concept. Typically, the debate revolves around whether the (democratic) state still possesses the capacity to 'steer' society, if not through legal power then through its control over resources and through reflecting collective interests. However, the literature seems preoccupied with studying the relations between various actors involved in governance and often lacks an account of who actually *defines* its objectives (Pierre and Peters 2000).

In spite of the often state-centred approaches to governance, I follow a definition of governance as a concept not restricted to state operations and institutions, but rather as a practice that crosses the traditional boundaries between the public and private sector. Hence, governance can be seen as formal and informal social and political practices that are the result of the interaction of multiple actors from state, market and civil society, each influencing each other. Such actors can for instance be government officials and politicians as well as NGOs or social movements, large enterprises or small CBOs, which all contribute to differing structures of governance depending on the context they operate in (Millstein 2007, Mogale 2003). Processes and politics of governance are not just played out in differing contexts, but also at various scales, whether global, regional, national or local. My focus on governance is not on 'steering' as such but rather on the politics concerned with governance. It is thus necessary to investigate the roles played by various actors, relations, partnerships and scale; the actual *politics of governance* as a process determining the making and implementation of policies in a society.

Why study governance in the context of HIV/AIDS?

So why should we employ a theoretical framework concerned with governance when doing research in the context of HIV/AIDS in South Africa? Whilst governance is often concerned with managing and sustaining the existing regime, the real test of governance is presented when changes in the regime are necessary to respond to new demands and challenges (Strand et al. 2005). HIV/AIDS can be seen as such a challenge. Both the state and civil society will have to find ways of dealing with a national crisis.

There is an increasing literature related to theoretical approaches to looking at governance and HIV/AIDS. HIV/AIDS and governance are intertwined in numerous ways, particularly when looking at the structure and politics of (local) governance. The structure and the practice of governance are crucial in determining how the epidemic is handled and partly for understanding its changes.

HIV/AIDS impacts on governance as well as governance impacts on HIV/AIDS. The epidemic can threaten democratic governance in the case of decreased citizens' support in government and participation in civil society (Barnett and Whiteside 2006). According to Barnett and Whiteside (2006), people who are infected or affected will be less occupied with how they are governed when the burden of illness and care is heavy. The number of people affected by the epidemic may lead to a lower degree of participation in elections, thus potentially erode political power balances in the long run (Strand et al. 2005). Simultaneously, a government that is unable to respond to challenges posed by the epidemic and lacks the leadership in critical situations can by citizens be perceived as politically weak and thus face a crisis of legitimacy. The way the HIV/AIDS epidemic is handled by governments could cause discontent and mistrust amongst fractions within the government and public officials as well as with civil society organisations. In the worst case scenario, this might contribute to political instability within countries with a relatively new democracy and a history of authoritarianism (Barnett and Whiteside 2006). A strong political leadership has been identified as key to fighting the epidemic (Jones 2004c).

The international approach to HIV/AIDS governance generally promotes democratic (good) governance as the ideal for dealing with the epidemic. Several policy directives have been

proposed for fighting HIV/AIDS. It is suggested that a response should be multi-sectoral, effectively implemented and coordinated, needs to recognise HIV/AIDS as a development issue, promote institutional capacity, generate financial resources and stakeholder involvement throughout all stages; designing, implementing, monitoring and evaluation (Strand et al. 2005). In summary, "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. 2005:42). Paradoxically, whilst central features in theory of democratic governance are that citizens should have a voice in the aspects of governance that affect them and should be empowered to hold governments' accountable, suggestions for HIV/AIDS governance are modest in allowing only a certain extent of influence by stakeholders. On the contrary, Strand et al. (2005) argues that international recommendations on HIV/AIDS governance could generate an undemocratic response.

Also Jones (2004a) indicates that the international approach to HIV/AIDS governance can be contradictive of ideals for democratic governance. The current system of governance does not necessarily open up channels of participation in the context of HIV/AIDS.

> Too often...the current development orthodoxy of human rights, good governance and democratisation, 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 co-ordination (Jones 2004a:181).

There is a need to investigate how the international governance structure and approach to HIV/AIDS is being imposed on local and national governance of HIV/AIDS. It can be argued that donors are driven by their respective country and international environments' approach to HIV/AIDS policies (Jones 2004b, Seckinelgin 2004). Furthermore, NGO policies are influenced by the prevailing international discourse indirectly contributing to HIV/AIDS policies being internationally designed. Seckinelgin (2004:290) considers "the international policy structure as an incipient governance system". HIV/AIDS governance is constituted by western language and technologies and becomes "a set of complex interconstitutive relations creating legitimacy for certain actors" (Seckinelgin 2004:290).

If the governance framework is set on an international level, national and particularly sub-national levels of government have little space for policy-making. HIV/AIDS governance is hence in many ways a top-down project, not just national to sub-national levels, but global to local. Hence, the problem with HIV/AIDS governance designed internationally is that it rarely fits the local context, the everyday realities of the people at the receiving end of a programme (Seckinelgin 2004). In other words, there is a serious disjuncture between the context of the policy maker and that of the people who are in fact infected and affected. It is this disjuncture that causes a potential ineffectiveness of interventions. The policy makers tend to make a number of assumptions about the agency of civil society, which then legitimises the mechanisms used in governance. The relationship between the donor and recipient "seems to be based on assumptions about people's nature, lives, and their needs rather than concrete evidence about how people change behaviour and what they need for this process" (Seckinelgin 2004:298).

How the structure and politics of governance impact on HIV/AIDS will vary depending on context. It will depend on state and leadership responses, the mobilisation and participation of civil society and other private actors' responses. HIV/AIDS policies need to be contextual already in the formulation process and not just in the implementation of such policies. In summary, there is a need to move towards analysing the politics of (local) governance and HIV/AIDS, taking into account the context in which a range of actors operate.

The politics of (local) governance

Much of the governance literature can be seen as apolitical, because it focuses on for instance institutions or formal structures rather than the politics shaping it. Yet "governance is fundamentally a political process and has everything to do with politics" (Millstein 2007:65). Hence there is a need to study governance not simply from a technocratic perspective. It is also important to understand governance politically, how various actors contribute to the process of governance.

Partnerships and participatory governance

The role of institutional reform and decentralisation have typically been the focus of local scale studies and thus ignored the actual politics of local governance. Such politics is

concerned with “transformations of structures, processes and practices of governance, identifications of actors and powers involved and how governance transformations interact with local social and political dynamics” (Millstein 2007:64). Governance can take various forms, depending on the context in which its structures and relations evolve. Influences on the type of governance can come from above and below. The structures can be set on a national (or international) scale through for instance public administrative reforms and democratisation brought about by an external demand for good governance. Simultaneously, governance can be challenged and influenced at a local scale through for instance rights-based mobilisation to ensure democratic rights (Friedman 2006, Millstein 2007). This calls for a discussion on the actual politics of governance, the impact of partnerships and power struggles that take place on various scales.

The decentralisation of power and decision-making to lower scales of government has been justified internationally as a way of increasing government efficiency, accountability and participation (Heller 2001). Whilst as Turner and Hulme (1997) identify centralised decision-making and power as a major obstacle to development for countries in the south due to central government being geographically and socially located too far from ‘the people’, a decentralisation of power to local governments could facilitate a better alignment of the decision-making centre with the local preferences (Heller 2001). It is assumed that in order to achieve a sustainable process of democratic decentralisation, civil society participation is crucial (Heller 2001).

As a result most governments have adopted a governance approach delegating authority between the centralised and decentralised institutions (Turner and Hulme 1997). This is also the case of South Africa, where local government has become central to the post-apartheid reconstruction and development process. The decentralisation is aimed at locating developmental initiatives with local authorities to encourage participation in policy making and implementation (May 2001, Mhone and Edigheji 2003). Participatory governance has strong roots in South Africa due to the anti-apartheid struggle where the majority of citizens were excluded from formal channels of participation in decision-making (Friedman 2006). The end of apartheid and the democratisation of South Africa opened up space and brought new opportunities for civil society actors to impact on government policy, whether by using the constitutional court or through engagement with government (Friedman and Mottiar 2006).

Policies on participatory approaches to governance are increasingly employed and opening up for the formal participation of societal actors in governance. However, the extent to which participation in governance is realised could depend on the local context:

> 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 decentralisation 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 2004:245).

It is also argued that 'partnerships' open up for the integration and collaboration of actors from the state, market and civil society in the process and politics of governance. The emphasis on the role of partnerships in governance is often associated with a neo-liberal discourse, where public-private partnerships are central in achieving development. Partnerships and participation are considered important means to ensure democratic governance (Millstein 2007). Where local government is obliged to ensure sustainability in the delivery of services, but is weak and has low capacity, there is a need to engage in partnerships with for instance the private sector or NGOs. Hence, for local governments to promote development, they need to seek partnerships with all actors that have the potential to contribute to the development of a particular area, both within formal and informal institutions and networks, within the state, civil society and the private sector (Mogale 2003). The role of partnerships in local governance is often celebrated as a way of involving 'the people' in governance, providing opportunities for society to keep the state and market accountable. However, the literature on partnerships and participatory governance tend to ignore the conflict and power struggles that take place between various groups or classes in society (Millstein 2007).

Even if policies on participation are intended to open up spaces and opportunities for organised parts of civil society (for instance social movements) to be included in the process of governance, the extent to which participatory governance as a tool is available and used by groups in society depends on both context and power relations. Participatory governance tools may in reality be unavailable to parts of the population and rather be used actively by local political elites in promoting their own interests. Such tools are often biased towards citizens

with the capacity to organise. Whilst some social movements may draw on various formal and informal networks to impact on governance, others lack the capacity to make use of the spaces that are opened through democratic and participatory governance. Hence, promoting participatory governance can also contribute to unequal power relations among civil society actors at the expense of weaker groups in society (Friedman 2006, Millstein 2007, Mogale 2003).

If participatory local governance is to be realised, all groups in the community need to be heard already in the process of decision-making. In order to achieve this ideal, there is a need to empower poor and marginalised groups on how to make use of their opportunities to influence on the process of decision-making (Mogale 2003). There is also a need to rethink participatory governance if the existence of formal channels of participation is in reality unavailable to large parts of the population. Friedman (2006) suggests that participation in governance is not just a matter of availability of formal mechanisms for participatory governance. It can also be a process where the excluded citizens make use of other channels to impact on governance, employing strategies of mobilisation and activism.

State-in-society

As discussed above, there are various actors both within the state and civil society that impact on governance. The 'state-in-society' is one approach to looking at the relational dynamics between the state and civil society which acknowledges that there a numerous actors involved in governance and multiple arenas where struggle for influence takes place. In a context of public-private partnerships and participatory governance, Migdal's theory, which emphasises the importance of understanding the state and the society in a relational perspective, can contribute to an understanding of the politics of governance. Simultaneously, it can be argued that his approach also calls for a further discussion of the importance of partnerships and participation for governance.

Joel Migdal (2001) rejects the dichotomy between state and society in governance and argues for a more nuanced approach to understanding social transformations which he labels "state-in-society". He argues that there are constant struggles over social control in every society and that there are multiple sites where domination[3] and change may be observed. Multiple groups

[3] By 'domination' Migdal refers to "the ability to gain obedience through the power of command" (Migdal 2001:98, footnote).

and coalitions (formal and informal) constantly struggle over meanings and rules that govern peoples' behaviour. The state is not the only force of social transformation. Battles over domination are fought both between the state and other powerful actors in society, within the state and within society. In other words, it can be argued that the structure of governance is the result of a process of interaction between various groups. The interaction leads to constant change in structure, goals and rules of the various actors.

> 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 2001:23).

It is misleading to consider the state as a representation of the people simply because of its territorial boundaries. The state is of dual character as it can operate as one single actor, but at the same time cooperates with and is influenced by various social actors. There are also groups within the state that work for opposite goals. Such groups often engage in coalitions with groups in society or other groups within the state (Migdal 2001). The interaction and struggle between both public and private actors, between state and groupings in society, can thus be argued to constitute the politics of governance.

Still, the state holds a central position in for instance negotiating with other states and also nationally it has a huge impact even in the most remote areas of a country, seen in anything from health care services, public schools, roads and sanitation. Nevertheless, the state is not necessarily in control of the social structure or the effective local leaders in the area as "...strong local figures and organizations with rules very different from those of the state" are likely to have an impact on policy-making and implementation (Migdal 2001:55). In summary, the state transforms society as well as society transforms the state.

Social forces can be formal or informal organisations, ranging from anything from families or churches, to social movements or large industrial enterprises. The power to influence, change or control behaviour and beliefs depends on a social organisation's capacity to make use of existing resources and to generate symbols that people attach themselves to. In order for a social force to achieve its goals, they need to form alliances and coalitions (Migdal 2001).

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 governance in the world" (Habib and Kotzé 2003:248). Civil society can be defined as "the organised expression of various interests and values operating in the triangular space between the family, state and the market" (Ballard et al. 2006:3). However there is a tendency to homogenise civil society. According to Habib (2003), this homogenisation is problematic because civil society organisations (CSOs) have diverse and sometimes contradictory agendas, both politically and socially. Civil society should hence be considered a heterogenic space. When recognising the heterogeneity of civil society, you can also recognise the plurality in state-civil society relations (Habib 2003, Habib and Kotzé 2003).

Habib and Kotzé (2003) make a distinction between CSOs that have taken a stance contrary to the government thus challenging the system and CSOs that have engaged in collaborations with the state thus working within the system. This division is referred to as '*the politics of opposition*' and '*the politics of engagement*'. The latter type of CSOs is seen as formal and larger service-delivery oriented NGOs. The former type is mobilisational CBOs or social movements. Social movements can be defined as "politically and/or socially directed collectives, often involving multiple organisations and networks, focused on changing one or more elements of the social, political and economic system within which they are located" (Ballard et al. 2006:3).

Nevertheless, this divide between engagement and oppositional CSOs is not rigid and can be transcended. To ensure reform and real improvement of the conditions of the marginalised communities you can not solely work against the state or solely engage in partnerships with government thus maintaining the *status quo*. On the contrary, to ensure the rights and service-delivery to marginalised communities in an increasingly neo-liberal world, there is a need to *combine* politics of engagement with politics of opposition (Habib 2003, Habib and Kotzé 2003).

Donors and NGOs in governance

The literature on governance is increasingly concerned with donor influence and the role of non-governmental actors in development. However, NGOs are often looked upon from a technocratic perspective and assumed to be an unproblematic way of securing service-

delivery. On the contrary, there is a need to investigate more carefully the role that NGOs play in partnerships and service delivery, taking into account the various contexts they operate in. In the latter part of this chapter, I argue that NGOs and donors are of the central actors in the governance of HIV/AIDS.

Theoretical contributions on the role of NGOs and donors are important in understanding governance. NGOs comprise many of the societal actors involved in the process and politics of governance. An understanding of donor-recipient discourses is furthermore important to take into consideration when studying the role of NGOs, particularly the ones of national and local character. Some of the impacts of donors and NGOs on the structure and politics of governance in development will be discussed below.

The role of NGOs in development

The shift towards neo-liberal economic strategies brought by globalisation has called for pulling back the state and promoting private sector-led development. International financial institutions advocating for a neo-liberal agenda have increasingly recognised NGOs as being actors of the private sector and as playing a central role in ensuring 'good governance'. This has called for engagement in partnerships with NGOs in order to enhance state efficiency and legitimacy. It is internationally recognised that in order to ensure a democratic development, an extensive mobilisation and involvement of civil society needs to take place (Mercer 2002, Pearce 1993).

In line with the definition used by Mercer (2002), the term 'NGO' is here referring to officially established organisations that have employed staff and are typically well-funded by international (and sometimes domestic) donors. NGOs may be either of international or national origins. CSOs on the other hand can be seen as a broader term, comprising both NGOs and CBOs as mentioned above. However, in this context I use the term 'CSOs' only to refer to organisations operating on a national or local level.

It is increasingly acknowledged that the shape governance takes can be explained not just by the changing power and role of the state, but by the changing role and powers of non-governmental actors (Millstein 2007). There is an ongoing debate about whether NGOs strengthen or weaken the state and civil society, if in fact NGOs can contribute to democratic development. The dominant liberal view is that civil society organisations provide the link

between the state and the grassroots. CSOs are assumed to be embedded in and reflecting the needs of the grassroots and to be able to holds states accountable. Hence, by engaging in partnerships with NGOs states can ensure accountability, legitimacy and transparency. In other words, they can ensure 'good governance'. If civil society is weak, democracy is likely to be threatened (Mercer 2002).

NGOs are typically assumed to be working with, representing and campaigning on behalf of poor and marginalised groups in society, contributing to a bottom-up democracy when they influence on public policy. However, much literature homogenise civil society and NGOs. On the contrary, there is a need to acknowledge that civil society might be characterised by competing interests and that there exist internal or inter-organisational power struggles (Habib and Kotzé 2003, Mercer 2002, Sabatini 2002). They do not necessarily constitute a democratic space separated from the state. Mercer suggests that civil society might be "a more problematic sphere of competing interests across both state and society" (Mercer 2002:11).

It can be argued that most of the theoretisation about the role of NGOs and civil society lacks an account of context. There is likely to be spatial and temporal diversity in the impact and roles played by NGOs. Civil society might be fragmented or weak and there is thus a need to investigate the context in which NGOs operate. NGOs are not necessarily driven by internal democracy. For instance, they might be under the authority of a strong leader and they might not constitute a space for wider participation in decision-making processes. NGOs could be headed by urban middle-class leaders and at the same time claim to be advocating for the rights of marginalised rural groups (Mercer 2002). In other words, NGOs are not necessarily representing or have a genuine understanding of marginalised grassroots-groups as assumed by many donors and the international community. On the contrary, the availability of external funding might actually distract them from promoting the interests of the poor and marginalised. Where NGOs are speeding up their activities in service delivery when donor funding becomes available, it might threaten their accountability to and legitimacy among the grassroots. Their accountability becomes directed upwards, to the funders, rather than downwards to the grassroots (Habib and Kotzé 2003, Mercer 2002, Sabatini 2002).

However, not all NGOs can be written off as elitist and/or opportunistic organisations. The involvement of NGOs could improve state efficiency in service-delivery where the latter failed. Yet it is necessary to study the 'agency' of NGOs in order to determine whether or not

they are able to contribute to sustainable development. Investigating the agency of NGOs is to uncover the roles of actors and analysing their ability to have a long-term impact with the interventions that are put in place (Mercer 2002). In other words, there needs to be careful evaluation of the above-mentioned factors, such as leadership and actual closeness to the grassroots.

International recognition of the crucial role of civil society adds pressure upon governments to contract-out service-delivery to NGOs in order to obtain international financial support (Seckinelgin 2004). Simultaneously, the neo-liberal discourse is pushing NGOs to become public service contractors. Mercer also notes that there is “a general trend towards focusing on donor-funded service provision at the expense of political activities” (Mercer 2002:14). The neo-liberal turn has led many NGOs to a move away from grassroots activism to being service-delivery providers (Mercer 2002).

Nevertheless, NGOs are not simply victims of the practice of governance, they do also engage in it. Whether through activism, engaging in debates or dialogues, NGOs attempt to influence on policy-making. To what extent they are able to influence will not just depend on the geographical level at which governance structures are set, but their capacity to influence the framework of thinking of for instance HIV/AIDS. Even if NGOs engage in for instance negotiations about their own role, accountability and implementation of policies, there is a question of whether or not they are able to impact on the overall framework of such (Seckinelgin 2004).

It seems to be recognised that to have an impact, NGOs cannot operate independently but need to engage themselves in partnerships. However, it is precisely when they engage themselves in partnerships that they depart from the closeness they are assumed to have with ‘the people’. To engage in partnerships, NGOs need to ‘construct’ their agenda and activities in a way that will make them targets for funding (Seckinelgin 2004). For instance, if a foreign donor is driven by the view that prevention is the most fruitful mean with which HIV/AIDS should be battled, the NGO will need to engage in activities directed at prevention in order to become a partner and receive funding. In other words, such partnerships are dominated by power imbalances. And it is these imbalances that can bring NGOs away from being mirrors of the realities and needs of the people, making them subjects of the governance structure, rather than actors with an influence on it.

According to Chopra and Ford (2005), external agents such as NGOs have the potential to construct spaces where people can discuss and develop action on community issues. The external agent can facilitate the creation and improvement of communication channels running between the community and the government or other agents of development, where people who do not normally communicate or cooperate can participate in developing and discussing the agenda in a safe space (Chopra and Ford 2005).

Donor-recipient discourses

"As an encounter between individuals with differing interests, resources and power...the aid relationship is prone to conflict" (Schneider and Gilson 1999:266). The success of donor-recipient relations/aid partnerships will thus depend on the ability to manage such potential conflicts. Both donor and recipients will go into a partnership coloured by the socio-political and economic contexts of their respective countries, creating a potential clash in interests (Schneider and Gilson 1999). Quite often in the donor-recipient discourse, differing interests and expectations are coupled with unequal balances in resources and power. In other words, there is a potential for conflict both over interests and struggle of power and influence.

One central factor influencing donor policy and programmes is what Jones (2004a) labels 'donor politics of the flag'. When donors fund or engage in a development project, they are under pressure to show the product of their aid. The programme in question needs to produce more or less visual outcomes for there to be a satisfaction about the investment. In other words, every investment should ideally be a showcase on the donor's behalf. There is a 'competition' being played out between various donors, as to who has the better policies.

Limited possibilities for domestically generated funding make numerous CSOs dependent on international donors (Sabatini 2002). "The reality is that donors wield enormous power over the political and economic development and direction of recipient organisations and countries" (Habib and Kotzé 2003:265). Unfortunately, looking at the major power donors possess in setting the agenda for recipients, most decisions on funding priorities are made by 'outsiders' located in a country of western origin. The dependency on external funding from donors practically mean they have the power to decide which CSOs are going to live and which are not. As a consequence, it is common that NGOs design their activities and aim to fit with the donor priorities for development. In other words, the way the donors identify and

view the current problems of development in a country is the way CSOs need to view it if they want to gain financial or technical support for their everyday activities and survival. They then engage in trade offs and accountability becomes first and foremost directed towards donors, not the people or the state. Hence development becomes donor-driven (Habib and Kotzé 2003).

One strategy in the recent years has been to encourage partnerships between donor and recipients. Such partnerships are also intended to create more horizontal relations by attempting to balance previous unequal power relations through partnerships (Jones 2004a). However, can donor-recipient partnerships ever be horizontal? According to Jones (2004a), the view of donors as the 'experts' is prevailing, creating limitations for genuine participation, feeling of ownership and responsibility of aid programmes.

In summary

Several approaches and meanings are attached to the concept of governance. It can be considered to be a steering concept, though there is disagreement over whom is steering society and how it is steered. Steering perspectives range from being of hierarchical nature towards network steering. However, the literature has been biased towards a technocratic character and there is a need to research not just the structures and process of governance, but also the politics that leads to such structures.

This theoretical framework highlights the importance of studying governance politically. The politics of governance is played out on various geographical scales and in multiple arenas, through various actors from both the state and society struggling for influence on the making an implementation of policies. Public-private partnerships and participatory governance seem to be playing increasingly important roles in governance, particularly in a context of (democratic) development. It is often assumed that participatory governance has the potential to open up political opportunities for collective actors. However, the extent to which the existence of a policy on participatory governance actually provides civil society actors with the means to participate and influence on governance will depend on the local context.
Simultaneously, civil society actors are not homogeneous. Civil society organisations are on the contrary diverse and can be engaging in either partnerships with the state (politics of

engagement) or challenging the state (politics of opposition). Yet, there are organisations that transcend this divide and combine engagement with opposition. This is a central theme for the second chapter of the analysis.

The international governance structure puts much emphasis on NGOs as a pivotal actor in implementing HIV/AIDS policies and programmes. However, local NGOs are often conditioned by international funding interest and framework of governance. NGOs will often adjust their agenda and activities to fit the preferences of donors, which jeopardizes their assumed 'closeness' to 'the people'.

Both in theory and practice, NGOs play a central role in democratic development. Still, it is a contested one. Based on the discussions above there is little doubt that also NGOs have a role in the politics of governance. The role of NGOs illustrates that governance should be approached as a two-sided concept. On the one hand, the participation of NGOs in governance can contribute to development of an area. On the other hand however, their participation can also create dependency. This will be a central theme of the last chapter of the analysis.

Governance is a well-suited framework for analysing development related policy arenas such as HIV/AIDS, because of the way the two are interconnected in various ways. The importance of the politics of (local) governance in a context of HIV/AIDS is an underlying theme of the analysis of this thesis.

3. POWER, POLITICS AND ETHICS:
DOING RESEARCH IN THE CONTEXT OF HIV/AIDS IN SOUTH AFRICA

This chapter outlines the choices I have made in relation to the fieldwork and the analysis, as well as reflections around central issues related to the fieldwork and choice of methodological framework. Central to this chapter are contextual challenges to conducting the research, regarding the nature of the topic and ethical concerns. The fieldwork was conducted in South Africa in February and March 2007. Most of the time of the fieldwork was spent in Lusikisiki (5 weeks), and I had additional interviews in Cape Town, East London, Bhisho and Durban before, during and after the time spent in Lusikisiki. Research permissions were collected from the organisations and institutions which required such; the Department of Health (DoH) and the Treatment Action Campaign (TAC).

Challenges to conducting research in the context of HIV/AIDS

Doing research related to HIV/AIDS and treatment in South Africa poses a number of challenges that need to be addressed. First and foremost, issues related to HIV/AIDS and treatment can be considered highly politicised in a South African context. HIV/AIDS has become a politicised topic in South Africa due to the history of 'AIDS denialism' with leading South African politicians, causing conflict with groups in civil society fighting for the right to treatment, as discussed in the introduction chapter of this thesis. The nature of the topic I was researching created several methodological challenges to my research. It presented barriers to accessing information, which has affected the character and quantity of the data collected for the analysis. The politicised nature of the topic is a central theme for this chapter.

Secondly, HIV/AIDS is an emotive topic. It is a topic that can bring forward emotions both with the interviewed and the researcher, and is also encapsulated in a lot of stigma and taboos due to the sexual mode of transmission. Traditionally and ideally, a human geographer is supposed to be objective rather than subjective, to be detached from emotions and to focus on reason rather than emotions as legitimating the researcher's integrity (Ansell and Van Blerk 2005). However, I argue that it is more or less impossible to stick only to reason when doing social research on sensitive and emotive topics. Hence it is almost impossible to maintain the

ideal of a detached researcher in researching issues related to HIV and AIDS. Fortunately, reason and emotions do not have to be opposites and could rather be intertwined (Ansell and Van Blerk 2005). Thus staying in touch with your emotions can also assist with reasoning and empathy can provide a better basis for analytical reasoning.

Due to employing observation as a secondary data collection method, I got close to many of the informants and was thus prone to end up in situations where people told personal experiences and stories. In such situations, it was challenging to stay completely detached from emotions. I also considered it unethical to appear completely untouched when people decided to open up and told very personal stories. However, it is a potential danger that you can quite easily fall into a counsellor-role rather than that of a researcher (Ansell and Van Blerk 2005). The balancing between these two roles was something I experienced as challenging as I became friends with many of my informants. The stories told were not directly relevant for the topic of the thesis, hence I am not referring to them in the text. Yet learning about peoples' stories and experiences can be considered an important factor for understanding the field, the relations and mechanisms that was operating in the local community.

Design and approach

Rationale of the approach

As argued above, doing research in the context of HIV/AIDS is challenging, partly due to the history of conflict over policies on treatment in South Africa. It required knowledge of the field and context in which the research was to take place. I had studied "Critical issues of HIV/AIDS and society" at the University of Cape Town in 2004 and was familiar with the history of and conflicts related to HIV/AIDS in the country. To gain knowledge about the Lusikisiki context, I spent the last couple of months before the fieldwork searching for news articles and partner reports about the programme and area. Simultaneously, I had previously worked as a volunteer in relation to the national HIV/AIDS programme in Benin. Hence, I had some knowledge about the making and implementation of such programmes and the mechanisms that are operating in an HIV/AIDS context.

According to Thagaard (2003), the approach and choices made during a research process is often influenced by the researcher's prior experience and abilities. Hence, my research has been influenced by my prior experience and knowledge about the field and related fields. I therefore acknowledge that my research can not be considered an objective reality. In line with Ragin (1994), I rather argue that researchers *construct representations* of social life, and that social research is just one among many ways of constructing such representations.

As there has been little empirical research done on the Lusikisiki HIV/AIDS programme, it was difficult to anticipate the nature of the data I collected during my research. However, the knowledge I had about HIV/AIDS as a politicised topic in the South African context, inspired me to read and make use of a theoretical approach concerned with governance, as outlined in the previous chapter. My knowledge of the topic also led me to the identification of a particular case.

A qualitative case study

I have designed my research as a case study with a qualitative orientation. A case study is a type of social research that implies in-depth research done on one or a few cases (Hammersley and Gomm 2000). Such a study is often employed when attempting to understand complex social phenomena. For instance, a governance-process, as in the case of the Lusikisiki HIV/AIDS programme, could be an example of such a complex process, which would not easily be captured by quantitative methods. Qualitative methods are useful when aiming to achieve an understanding of a social phenomena, behaviour and interaction between people (Thagaard 2003). Hence, in order to understand and capture the relational dynamics operating between the partners of the Lusikisiki programme, to ask questions of how and why the process of governance takes place (Yin 2003), I have used a qualitative case study approach to the research. One of the strengths of the case study is that it opens up for the use of several qualitative methods, from looking at documents and other artefacts to doing observation and interviews (Yin 2003). In order to access information during my fieldwork I have chosen to focus on the two latter ways of doing research.

As indicated above, the case that I am studying is a local governance process experienced in relation to the Lusikisiki HIV/AIDS programme. The programme had a few months prior to my fieldwork experienced a transition from NGO to government run programme. Hence, there was a need for investigating how the transition came about, which changes happened,

and how people felt about them. With regards to doing observation, I was quite fortunate that the weeks I spent in Lusikisiki were full of TAC activities, thus the timing presented an excellent opportunity to use such a method of research. However, the time of the research was a time where people felt that all eyes were on Lusikisiki. The MSF withdrawal and recent changes in the programme had created an atmosphere where people were facing an uncertain future of the programme. This is thus likely to have affected the views and reflections of the informants, hence also the character of the data I collected. The uncertainty could have given first and foremost the civil society actors a more pessimistic attitude regarding the cooperation, whilst as for the DoH they most likely had an interest in appearing as capable and liable as possible in managing and sustaining the programme thus downplaying their challenges and romanticising the cooperation with other actors.

Positioning and accessing information

Due to the history of conflict between the DoH and TAC, as outlined in the introduction chapter, talking about TAC was a sensitive issue. I had to be cautious with my mentioning of the organisation when interviewing government officials or other people related to the DoH. I never lied about my intentions, but I needed to be careful in my approach when asking questions related to TAC. Such questions were always asked towards the end of the interviews, unless the informants raised related topics themselves.

Regarding the sensitive nature of the topic I was researching, I knew it would be challenging approaching and scheduling interviews with the DoH and I was warned about this upon my arrival in South Africa. I was for instance told a story about a group of Dutch journalists that had arrived in Lusikisiki and started interviewing people without the department's permission. It resulted in a lot of problems with the local DoH, which fiercely insisting on them leaving. In order to avoid any such problems, shortly after my arrival in Lusikisiki, I went straight to the head of the DoH and introduced myself. However, I had to make sure that my research was by no means perceived as a threat, hence I had to position myself as humble and harmless I possibly could. My approach to the DoH seemed well accepted and they even assisted me in contacting the provincial DoH for research permission. The head of the local DoH can thus be perceived as a 'gatekeeper'. This person was in the official position to handle inquiries for a

particular group of informants (government officials and public health care workers), whom I had to pass in order to access other people working in the field (Cloke et al. 2004).

Nevertheless, it was challenging to access information from the DoH. It took me 2-3 weeks of telephone calls, faxes, and a day-trip to Bhisho (where the Eastern Cape DoH is located) in order to collect the research permission. The DoH was not only reluctant to give me research permission; they were also reluctant to provide me with documentation around the programme. This has obviously affected the quantity and nature of the data I have collected. I knew the DoH were in possession of documents and reports related to the programme, however, when I requested such documents they would variously reply that they did not have any documents that would be of use for me or that they did not know where they were stored. Hence most documents I refer to are publicised reports. The lack of documents available has been mitigated through a triangulation of other methods of data collection, which will be elaborated on below.

Also nurses, doctors and others employed by the DoH and working in the clinics or hospital seemed to have been put under a lot of restrictions by their employer on sharing of information and were afraid of the consequences if they did so. This has most likely affected the nature of answers given to my questions and thus the nature of information gathered in the fieldwork, at least from the DoH employees. They could have been withholding information from me if fearing negative consequences from their superiors for revealing it. Yet, when I presented people with the research permission and gave them the option of answering the questions they felt comfortable with, most people agreed to talk to me.

I tried mitigating the impact of fears discussed above by ensuring all informants anonymity and eventually refrained from using a tape recorder in such situations. Writing notes instead of using a tape recorder meant that I could have missed out on important points the informant made. It also made a comparison with the recorded and transcribed interviews more challenging. A tape recorder is argued to be the best way to ‘capture’ everything said in an interview. However, the presence of a tape-recorder sometimes creates a more formal situation where the answers of the informant are more ‘guarded’ than they would have been without the presence of it (Cloke et al. 2004). Hence, I made a choice of using a recorder or simply writing notes depending on the type of informant I was facing. A choice was made

based their position and whether or not they were familiar with or would be comfortable with the presence of a recorder.

Due to Lusikisiki being a small community, I always had to be cautious with who I talked to, where and about what. As I was the only young, white and blond woman in the area, people quickly got to know who I was and it was difficult to ‘hide’. Hence I always had to be careful not to jeopardize the anonymity of my informants.

Due to Lusikisiki being a ‘deep’ rural area, I experienced challenges of transport, particularly in reaching the clinics. As the HIV/AIDS Adherence Counsellors’ Organisation (HAACO) was in possession of transport and regularly went to the clinics, they were an easy way of accessing interviews with clinic personnel. However, arriving at the clinics together with HAACO could have influenced the situation both in a positive and a negative direction. HAACO can be seen as a door opener, as the organisation was well known at the clinics and assisted the nurses in communicating messages with the DoH, but it could also have affected the data collected in the interviews with the adherence counsellors. Despite my insistence on their anonymity, it is not unlikely that some feared I might somehow reveal their views to their ‘employer’ after the interview. They could thus have refrained from sharing all their reflections and challenges with me, particularly regarding their own organisation and work.

Sources and methods for data collection

Observation and informal talks

Due to the novelty of the Lusikisiki HIV/AIDS programme and the lack of empirical research on the case, I started the fieldwork by doing observation and informal talks to prepare myself for the coming interviews. Through observation I was able to gain important information about both actions and relations between people (Thagaard 2003). The informal talks were useful for getting to know the basics of the programme and nature of the relations and cooperation. According to Cloke et al. (2004:152), “the unexpected ‘chat’ with key individuals has often proved to be a most fruitful research moment”. The bulk of the observation and informal talks is not explicitly referred to in the analysis, however this approach in the beginning of the fieldwork provided me with information about whom to

interview and which questions to ask. Simultaneously it provided me with a foundation for assessing the information from the interviews.

Through a method of observation I got a great opportunity to experience the way the partners worked and behaved in relation to each other and the community. I got access to for instance TACs mobilisations during the time of my stay in Lusikisiki, attended a HAACO weekend seminar where all partners of the programme had their representatives, attended a DoH public prevention day, got to go to meetings, went to visit the clinics and travel around Lusikisiki with the partners. However, through observation and informal talks I also became friends with many of the informants. In this way I gained the informants trust, but it can also be argued that it made me less objective in my research.

Qualitative interviews

Using a quantitative method for this study was not feasible, particularly as the study values the various opinions of the partners in the programme, their perspectives on the situation and each other. In contrast, the qualitative interview is a way of learning about peoples' perceptions and opinions, their experiences and reflections around their situation (Kvale 2001, Thagaard 2003). Still, the qualitative interview is not communication based on reciprocal relations, because it is the interviewer who defines and controls the situation. The information generated from the interview will be subjective, as it depends on both the person interviewed as well as the interviewer. Nevertheless, by using qualitative interviews the researcher can capture the diversity and variations in opinions around a topic (Kvale 2001). Hence, the interview is a central way of generating knowledge of the social world.

An interview guide could be either structured (detailed), semi-structured or non-structured (Kvale 2001). I started my fieldwork with a relatively structured interview guide, but gradually moved towards an un-structured guide after becoming more experienced with the field and with conducting interviews (see appendix 2, illustrating themes for the interviews). This guide was adjusted to fit the type of informant upfront of every interview. Contrary to the structured interview guide, I felt the unstructured guide made the interview situation less formal and more of an open dialogue between the informant and me. The chronological order of the topics discussed and questions asked thus came as a consequence of the turns and course of the interview. Hence the interview guide was reduced to being more of a checklist towards the end of the interview.

Sources for interviews

Prior to my departure for fieldwork in South Africa, I had written a provisional list of people I wanted to talk to. Changes in the list were made based on the observation, informal talks and a 'preparatory' interview conducted with MSF (see appendix 1). Upon my arrival in South Africa, I wanted to get an overview of the situation in Lusikisiki, the partners, relations and the recent changes in the programme, before departing for Lusikisiki. Hence, I started the fieldwork by conducting an interview in mid-February with MSF in Cape Town. The other interviews were conducted in March 2007. I have conducted interviews with 6 local TAC members and 3 provincial TAC members. Simultaneously, I have conducted interviews with 6 HAACO members (where 4 out of 6 were working as adherence counsellors in the clinics and hospital). I have conducted interviews with one manager in the provincial DoH, two managers in the local DoH, 1 hospital doctor and 3 nurses working in the Lusikisiki clinics employed by the DoH. Additionally, I interviewed a key person in the provincial AIDS council, a representative for a central committee within the EC government and an academic source due to his knowledge of the area and programme. Ideally I should have interviewed more people within the DoH, but the challenges in getting permission and the sensitive nature of the topic made it hard to access informants within the DoH. And when approaching MSF, the organisation insisted I could only have one interview as they all spoke on behalf of each other. However, some of my informants in Lusikisiki were previously local MSF employees, thus I got the opportunity to confirm the information from the first interview.

The majority of my informants are women. The reason behind the largely female group of informants can be explained by looking at the gender balance within the groups that I interviewed. Both the DoH and the civil society organisations have a dominantly female membership base, leadership and clinic employees. Having a gender balance in the selection of informants would not be a reflection of the realities of the programme and partners.

Interview situation

The interviews variously lasted from 30 minutes to almost 2 hours. Due to the sensitive nature of the topic they were all conducted behind closed doors. As mentioned above, the interview situation is characterised by an unbalanced power relation, as it is the interviewer who defines and controls the interview (Kvale 2001). However, in one of the interviews I experienced a reverse situation, where it was actually the informant who took control. After I had formally

ended the interview, the informant requested for the tape recorder to once again be turned on. She then started asking me questions about my *real* intentions with the research I was doing. I always maintained that I have nothing to hide, so I had no issues with the converted roles. The fact that she felt a need to question me about my intentions can be an indicator of two things. First of all, she felt uncomfortable in the situation and wanted to put me in a similar position to see how I reacted. Secondly, due to the sensitive topic and fear that information could be misused, she wanted to have on tape who I really was and why I was really doing this. Personally I think it was a mix of both. Yet, after less than five minutes, she seemed content and even though I volunteered to give her copies of the tape, she said it was not necessary. Nevertheless, I had one other informant who requested a copy of the recordings with her as a safety guard. She was afraid of any consequences from her superiors if the information was to be misused. I thus respected her request.

Language barriers

Lusikisiki is a Xhosa-speaking area, where a large part of the population is not fluent in English. Unfortunately, it was not possible to find and provide for a full-time interpreter to stay with me during several weeks of fieldwork in Lusikisiki. Simultaneously, due to the sensitive nature of the topic and for reasons of anonymity I could not employ a local person. This is likely to have affected the data collection to a certain extent as there were situations and conversations taking place which I did not always understand or could have misinterpreted. During the interviews, language did present a significant barrier. There was only one informant that in a couple incidents seemed to have a problem expressing him/herself in English. All my informants spoke English, though the informants with a higher level of education were somewhat more confident with the use of the language. In this particular study, I do not feel that the absence of an interpreter inhibited the interviews. To a certain extent it limited the gains from the observation, as I on some occasions needed to request participants to translate for me. Fortunately, in most cases people would volunteer to translate for me, but I am likely to have missed out on information due to the language barrier in the observation.

Documents and secondary sources

As mentioned above, there was little empirical research done in relation to the Lusikisiki programme prior to my fieldwork. Prior to the fieldwork I collected all articles and reports about the programme accessible on the internet, for instance the joint rapport by MSF and

DoH published at the time of the formal handover of the Lusikisiki programme: "Achieving and Sustaining Universal Access to Antiretrovirals in Rural Areas. The Primary Health Care Approach to HIV services in Lusikisiki, Eastern Cape". And during the fieldwork I requested additional documents from the partners of the programme, for instance MSFs project proposal to the DoH and HAACOs memorandum of understanding with the DoH.

Some reports such as MSFs "Help Wanted" have been published and collected after my fieldwork. I have made use of literature on South African HIV/AIDS policy such as articles by Mandisa Mbali (2003), Virginia Van der Vliet (2004) and a book by Peter Fourie (2006). Simultaneously, I have made use of academic articles written about TAC at a national level. These include Steven Friedman and Shauna Mottiar's (2004) "A moral to the tale: The Treatment Action Campaign and the Politics of HIV/AIDS" and Steven Robin's (2004a) "Long live Zackie, long live: AIDS Activism, Science and Citizenship after Apartheid". Newspaper articles and other articles published in journals concerned with the Lusikisiki programme such as Belinda Beresford's (2004) "Pioneering treatment access in a rural area of South Africa" and Steven Robins' (2004b) "ARVs bring hope to Pondoland" have been used to supplement my findings. Additional secondary sources and documents will be revealed in the list of references for this thesis.

Processing and analysing the data

In preparing for the analysis, as the majority of the interviews were recorded, they also had to be transcribed. The process of transcribing was done shortly after the interviews when there was time available. The remaining interviews were transcribed following my return to Norway. I used an Mp3 player with an additional microphone for recording the interviews, thus the quality of the recordings was generally good.

Analytical approach

Analysis of the data is not a separate part of a research project, but should rather be considered as a continuous process throughout the study. It is not just a matter of classifying or categorizing data. Analysis is first and foremost about representation of or reconstructing social phenomena. Still, the choices made in the analysis, the mode of writing and the representations I use can be as significant and powerful as the actual content of the data

collected (Coffey and Atkinson 1996, Ragin 1994). The arguments made in the analysis of this thesis should therefore not be considered an objective truth.

Simultaneously, it is argued that an analysis could be used to test a theory or generate new theories (Kvale 2001). As the Lusikisiki HIV/AIDS programme was only initiated in late 2002, there was not much information to be gained about the programme prior to the fieldwork. The only available reports about the programme originated with either the main partners or the media. Hence, due to the difficulty of anticipating the character of the data that would be gathered in South Africa, it was difficult to develop a thorough theoretical framework prior to the fieldwork. As mentioned previously, I was inspired by governance-theories when preparing for the fieldwork. However, the theoretical framework of this thesis was modified after returning from the field and investigating the data collected. In other words, the theory affected the data collected and *vice versa*. This is in line with Ragin (1994) who argues that the analysis of social phenomena is a process characterised by a dialogue between theory and data collected in the field.

Analytic generalisation

Which lessons can be learned when conducting a case study? There are conflicting opinions regarding the question of generalisation in a single-case study. Whilst some argue a case study could be used to test a theory or to draw generalisations about a field, others argue it should only be used for studying the unique.

However, it is necessary to distinguish between the types of generalisations. The most common form of generalisation is *statistical* generalisation. In order to perform such, you need a random selection of people from a population. This would not be possible with a qualitative case study (Kvale 2001, Yin 2003). Another way of generalisation is labelled *analytic* generalisation. This implies that the researcher provides a justification of the extent to which the conclusions from the research can contribute to an understanding of and preview of other situations. The researcher states the evidence so that the reader can herself judge the validity of such a generalisation (Kvale 2001, Yin 2003). Based on the arguments lined out above, I do not consider this study to be of any significance for making a statistical generalisation. However my findings can be used to draw analytic generalisations. I argue that the governance process experienced in relation to the Lusikisiki programme can be illustrative of what is happening or what could happen in other HIV/AIDS programmes in South Africa

taking time and spatial limitations into account. The extent to which this study can contribute to an understanding of other situations will be discussed in the concluding chapter of this thesis.

Ethical concerns

Ethical considerations and decisions need to be made from initiation of the project and throughout the research process (Kvale 2001). In order to make sure my research was ethically justifiable in a South African context, I handed in all my paperwork and research details and collected an ethical clearance from the South African University of Fort Hare. I also collected research permissions both from the provincial DoH and from the national TAC office. HAACO was a new and local organisation, thus they had no such prerequisites for allowing me to conduct research. Neither did MSF.

Due to the sensitive nature of the topic, I have reflected a lot on ethical considerations prior to, during and after the fieldwork. Some of the ethical challenges I faced and related choices I made will be discussed below.

Informed consent, anonymity and confidentiality

Due to conducting research in a small and transparent place in a corner of South Africa and due to commencing the fieldwork by observation and informal interviews, the majority of my informants were already aware of whom I was and why I was there prior to the interview situation. However I made sure that all my informants were informed about the main features of my research project before they approved of giving interviews and that they could refrain from answering questions. They were also asked if they were comfortable with me recording the interviews. A couple of informants requested not to be taped, which I respected. Simultaneously, I quickly sensed that for most of the health workers in the clinics, the recorder constituted a formal and tense setting, and thus decided to simply make notes during these interviews. It produced good results as the informants seemed more relaxed and opened up in the absence of the recorder.

I have also chosen to rely on principles of anonymity and confidentiality in my research. Confidentiality is based upon principles protecting an informant's privacy and implies that the

researcher makes sure that data that can be connected to a persons' identity will not be publicised (Kvale 2001). Even though several of my informants said they could be quoted by their name, some informants requested not to. However, due to respect of the privacy of those who were afraid to have their identity known, I have chosen to make all informants anonymous in the thesis. Lusikisiki is a relatively small place, where most people working within the health sector know each other. Ensuring anonymity of the informants is therefore very important. Simultaneously, due to the sensitive nature of the topic, I considered it better if all informants remained anonymous, as I do not wish for my research to be the cause of any problems or worsening relations between the informants or the partners of the programme.

Ethical barriers to the use of information

Through staying in a small community and pursuing observation and informal talks as methods for data collection, I was in a situation where I became friends with some of my informants. This has implications both as it makes me more subjective in my analysis and because it affects my integrity as a researcher as it did not feel ethically justifiable to use all the information collected.

Even when I told people about my thesis and asked if I could write things that they said, I wondered if they forgot about it after a few minutes, or if they did not really understand that what I wrote could have consequences when other people read it. There were things that informants would say, which I myself would never have said in such a setting. It is not unlikely that people felt more comfortable when there was an informal setting without a tape recorder taking place as a conversation, rather than an actual interview. Some probably considered me a friend and I had thus gained their trust. This raises ethical concerns about using the information retrieved from these settings.

For instance, I experienced getting information of activities going on which I knew were not in accordance with South African laws and regulations. Revealing such information could harm not just the informants, but also the programme and the trust between the partners. I thus decided not to make use of the controversial information I got access to in these situations even if limits my integrity as a researcher. Out of respect for my informants and having reflected on the consequences of publicising the information, I did not find it ethically justifiable to reveal all the data I collected.

In summary, I have tried my best to maintain ethical standards and guidelines throughout the research, but there are however some ethical considerations that are difficult for me to make as a white and female foreigner in an unfamiliar setting, particularly in a context where the topic for the research is as sensitive and politicised as that of HIV/AIDS in South Africa.

Assessing the quality of the research

This chapter has outlined the methodological and ethical considerations and choices I have made throughout the research process. This thesis is thus a result of the meeting between me as a researcher and a context of a politicised and sensitive case. The politicisation of HIV/AIDS and the treatment debate presented difficulties of accessing information from documents and informants, affecting the quantity, character and nature of data collected. Simultaneously my role, perceptions and positioning as a researcher has in many ways affected the data collection and the analysis, hence the conclusions made can not be considered objective. Then what makes my research credible? Rather than engaging in a discussion on which terms are suitable for assessing the quality of the research, I have chosen to look at some points that I regard as useful for assessing its quality. Adapted from Thagaard (2003), I argue that the credibility of this research lies in the descriptions and reflections of how the data has been collected and processed in the course of the research. Hence I have outlined the sources and methods for data collection and reflected on the context in which data has been collected and analysed.

Despite researching in a politicised context creating barriers of access to information, I have managed to conduct an extensive fieldwork. Even if it took time, I collected the necessary research permissions and gained access to informants from the central partners of the programme. Secondly, I used a triangulation between different methods of data collection through observation, informal talks and interviews. The triangulation of methods mitigates the lack of empirical research previously done on the case to support my findings. And the fact that the informants answers to the main questions I posed reached a point where every answer given seemed to support a statement made in a previous interview, makes me confident that my approach and selection of informants was sufficient.

The sensitive and politicised nature of the topic also presented with me a range of ethical challenges, which ‘haunted’ me throughout the research process. In order to avoid any negative consequences for my informants, I have decided to make everyone anonymous even if they explicitly said they could be quoted by their name. I also made a deliberate choice of not disclosing all the information I was presented with in the informal talks. As I considered the information harmful to the programme and the relations, I did not find it ethically justifiable to reveal it and that this study should ruin the future and follow-up of the programme. Nevertheless, the ethical approach I had to the research created a setting where the informants could open up without having consequences for their anonymity or roles in the programme.

Based on the discussions above, I argue that the ethical and methodological considerations and choices made provide the basis for a sound analysis of the case presented in the three coming chapters of this thesis.

4. FROM THE POLITICS TO THE GOVERNANCE OF TREATMENT

The theoretical framework of this thesis emphasised the need to study governance politically, as there are several actors that influence the structure and process of governance. This chapter regards the partnerships and collaboration between 3 central actors in the Lusikisiki HIV/AIDS programme; Médecins Sans Frontières (MSF), the Treatment Action Campaign (TAC) and the Department of Health (DoH). Underpinning this chapter is a move from the politics towards the governance of treatment with Anti-Retro Virals (ARVs). Prior to the initiation of the Lusikisiki programme, the South African state and civil society actors were divided over the roll-out and provision ARVs. There was debate around the politics of treatment, as discussed in the introduction chapter. With the launch of a new national plan committing the government to roll out ARVs, the debate is increasingly concerned with the governance of treatment. How can such treatment be successfully rolled out? Who should have a saying and participate in ensuring the roll-out? I argue that the case of Lusikisiki is illustrative of a transition from a focus on the politics to the governance of treatment.

This chapter reflects the first research question regarding firstly the partnerships and collaboration and secondly the main challenges to cooperation. The chapter starts with an introduction to the three central partners involved in the governance of HIV/AIDS in Lusikisiki. The initiation of the programme and the actors' engagement in partnerships to ensure the roll-out is illustrative of a move from the politics towards the governance of treatment. Finally, some of the implications related to the governance of treatment in Lusikisiki will be discussed, through looking at challenges to cooperation between the partners in the programme. These challenges are related to discussions on partnerships, the dual state, and the role of donors and NGOs, as outlined in the theoretical framework.

The partnerships and collaboration

Partners and agendas

The Department of Health

The Department of Health (DoH) is a body under the South African Ministry of Health. The South African DoH's mission 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).

The South African health sector is characterised by a 3-level divide between national, provincial and district (local). It is the Department of Health (DoH) which runs the national HIV/AIDS plan and programme. Policies are generally designed at the national level (at least the broad policy framework), whilst it is the province that is assigned the responsibility for implementation of policy. The national DoH sets norms and standards for service provision, then collects and distributes the available funds to the provinces who then decide where to allocate the funds (Jones 2004c, Mogale 2003, Schneider and Gilson 1999).

In Lusikisiki, the local DoH is a representative for the OR Tambo District DoH covering one of their Local Service Areas (LSA). The new system of a district level of government was introduced in 2006 with the intention that local government should no longer report directly to the Province, but via the District level which would then communicate the messages to the provincial government. However, it is the local DoH with support from the provincial DoH that has been operative and central in Lusikisiki before and throughout the HIV/AIDS programme.[4] Hence, when referring to the local DoH, I am referring to the DoH which is a representative of the District with an office located in Lusikisiki.

The Treatment Action Campaign

The South Africa based Treatment Action Campaign (TAC) was established on the international human rights day, December 10th 1998. They were provoked by the non-accessibility to treatment for people living with HIV/AIDS in South Africa, as a result of the big pharmaceutical companies' prices and monopoly on treatment and the government's reluctance to roll-out ARVs to its people. Their aim was to campaign for access to affordable treatment for all South Africans through raising public awareness and understanding around the issues related to treatment of HIV/AIDS. They use methods running from street activism and demonstrations to action in court, and can be easily recognised by their posters and pamphlets (Friedman and Mottiar 2004, Robins 2004a, Van der Vliet 2004). In other words,

[4] Interview DoH Lusikisiki 1 14.03.07, interview DoH Lusikisiki 2 25.03.07

their engagement and social mobilisation places TAC in a position as a central civil society actor concerned with the politics and governance of treatment in South Africa.

Simultaneously it can be argued that TAC is also a locally embedded organisation that has translated national campaigns into local events. TAC has engaged in and are supporting local projects such as the treatment collaboration with MSF and the local DoH providing ARVs in Khayelitsha of Cape Town from 2001. They have been working at the community level in Khayelitsha supporting patients' adherence to treatment, fighting stigma and discrimination (MSF 2005). TAC has established provincial offices and some district offices around South Africa, including the office based in Lusikisiki from 2003. Sub-departments called 'branches' are operating below the district offices. In other words, there are 4 geographical levels of offices, ranging from national to provincial and district to branch level. The branches are central to the local embededness of the organisation developing community responses to HIV/AIDS.

Médecins Sans Frontières

The international non-governmental organisation of Médecins Sans Frontières (MSF) "is an independent humanitarian medical aid agency, committed to two objectives: providing medical care wherever needed, regardless of race, religion, politics or sex and raising awareness of the plight of the people we help" (MSF 2007a). MSF is also concerned with acting as a witness for the people it serves and will thus voice-up in public or private in a context where fundamental human rights are not secured. Through ensuring that the majority of their funding comes from the general public, they aim to be neutral and independent of individual governments (MSF 2007c).

MSF has been involved in various projects around the world since its establishment in 1971. MSF South Africa is one of the organisations' 19 sections. MSF worked in South Africa in the 1980s, but then left only to return in 1999 to assist People Living With HIV/AIDS (PLWHA). Their presence in South Africa was consolidated by opening a new office in Johannesburg in 2007 (MSF 2007b, MSF 2007c).

Motives for partnerships and collaboration

The rationalities underpinning the initiating of the Lusikisiki HIV/AIDS programme can be explained by several factors. First and foremost, the political climate in the context of

treatment for HIV/AIDS in South Africa was changing, as a new plan for rolling out ARVs was in progress. Secondly, MSF had taken a lead in supporting and providing ARVs in South Africa, as the MSF-initiated HIV/AIDS pilot in Khayelitsha (Cape Town) had produced good results with regards to treatment roll-out (Beresford 2004, Robins 2004b). In this context, critics were claiming that despite MSF succeeding in Khayelitsha, such results would be much harder to produce in a rural context.

Changes in the political climate

The initiation of the Lusikisiki HIV/AIDS programme can partly be explained as a result of a changing political space. As outlined in the introduction chapter, South African politicians, government officials, medical experts and civil society had long been divided over HIV/AIDS causes and policies and fierce debates ravaged the public space (Fourie 2006, Van der Vliet 2004). By 2003-4, the debate was subsiding. After years of debating the right to treatment and whether or not government was obliged to provide treatment to the people, the drafting of a national plan including the provision of ARVs was in progress as MSF was building infrastructure, mobilising resources and preparing the roll-out of ARVs in Lusikisiki. In other words, the political climate was changing and there was an increasing political will to succeed in rolling out and achieving universal access to ARVs. According to Beresford (2004:284), "national government's endorsement of a country-wide AIDS treatment plan including antiretrovirals, has reduced some of the initial hostility to the MSF programme". For instance, local nurses were previously afraid of handling ARVs because they considered them 'politically contentious'. However this has changed after the implementation of the programme (Beresford 2004).

Breaking down rural barriers to treatment

Simultaneously, it can be argued that MSF was motivated to initiating a rural treatment roll-out, as critics claimed that it was not possible outside an urban context such as Khayelitsha. For instance Robins (2004a) argued that it remained to be seen to what extent MSF was able to export the urban (Khayelitsha) strategies of treatment roll-out to rural areas of the former homelands where myths and patriarchical relations are driving the spread of the epidemic. It was precisely this type of statements and disbelief in the success of a rural treatment roll-out that triggered the MSF initiation of the Lusikisiki programme (Beresford 2004, Robins 2004b). The organisation decided on designing and implementing a model to convince the critical voices and approached the Eastern Cape DoH. "They agreed on Lusikisiki as the site

for the programme because of its deep rural nature, high HIV prevalence and history of underdevelopment" (MSF and DoH 2006:3)

MSFs desire to prove their ability to succeed in rolling out a rural treatment programme, can be explained by picking up on some of the arguments presented in the theoretical framework. In order to sustain financial support, they are under pressure to show the product of their aid. As there is a competition being played out between donors or NGOs, every project should ideally be a showcase of an organisation's ability to perform small miracles. MSF was originally divided regarding the initiation of the Lusikisiki programme. Some people within MSF in South Africa argued to Dr Reuter, who was to become the head of mission for MSF in Lusikisiki, that "MSF is not here to provide services in the country, we are here to have a demonstration model" (Reuter quoted in MSF and NMF 2006:12). However, due to the critical voices claiming that MSF would be less likely to succeed in rolling out treatment in a rural area, MSF was motivated into embarking on this task. And Lusikisiki became their new showcase. "If it works in Lusikisiki, it can work anywhere in South Africa" (Head of MSF in South Africa quoted in IRIN Plus News 2004:17).

The Mandela factor

Another important factor that made the Lusikisiki programme possible was a partnership with Nelson Mandela Foundation (NMF), which provided both financial resources and political legitimacy needed to roll out a treatment programme. The involvement of NMF has primarily been as a financial supporter of the programme through MSF. Their funding enabled MSF to embark on a rural treatment roll-out.[5] However, it was also a politically strategic partnership for MSF. Involving an organisation bearing Mandela's name created an interest in the programme regionally and nationally.

Mandela had previously attempted to voice up in the national debates around HIV/AIDS and treatment in South Africa, but he did not receive a warm welcome with the ANC political leadership. "Mandela became vocal...and he was silenced by the moral police. He couldn't be vocal decided Mbeki, because he wasn't a President anymore."[6] According to MSF,[7] this is why he decided to support their organisation. If he could not be vocal about it, he would at

[5] Interview MSF 14.02.07
[6] Interview MSF 14.02.07
[7] Interview MSF 14.02.07

least assist others working in the field. And MSF emphasised that the partnership with Mandela's foundation has created a political space and acted as a 'political shield' both for MSF and the programme, particularly as they initiated the programme at a time when there was a lack of national policy on access to ARVs.[8]

The Mandela involvement also created an acceptance of the programme within the community. Nelson Mandela seems to be a role model, an icon, all over the country, but even more so in the former Transkei, part of the former 'homelands', where Mandela himself has his origins. "When Mandela speaks then everybody follows."[9] Then who could better create an acceptance and publicity of the programme in Lusikisiki than Mandela? The fact that Nelson Mandela came to the launch of the programme in late 2003, that he publicly gave the first patient her ARVs, also seems to have been of great importance for the acceptance of the programme locally. When news of Mandela's visit arrived everyone was saying "Madiba is coming! Madiba is in Lusikisiki!".[10] He gave his blessing and support to the programme. Everyone saw him giving out ARVs, thus stating that ARVs work, and are not toxic as the government had previously claimed.[11]

In summary, Nelson Mandela's name and mark on the programme was of great importance for its acceptance and successful implementation, both in the political context and at the community level.

The role of an individual

In addition to Nelson Mandela, there are also other individuals that have been central to initiating the programme. Dr Hermann Reuter was a former TAC provincial coordinator, but later started working with the MSF run Khayelitsha programme. It was Dr Hermann (as he is called by the people in Lusikisiki) who first discussed the idea of building a rural HIV/AIDS treatment programme with Nelson Mandela, when Mandela came to visit the Khayelitsha programme. Dr Herman did much of the planning, training and implementation of the programme himself. He was head of the Lusikisiki MSF office, lived and worked in the area until the formal hand-over of the programme in 2006 (MSF and NMF 2006).[12]

[8] Interview MSF 14.02.07
[9] Interview MSF 14.02.07
[10] Interview Adherence Counsellor 1 05.03.07
[11] Interview Adherence Counsellor 1 05.03.07
[12] Interview MSF 14.02.07

The politics of partnerships

The changing political climate in the context of HIV/AIDS and a new national plan for the roll-out of ARVs led to an increasing focus on the governance of treatment. For Lusikisiki, the shift from a focus on the politics towards the governance of treatment can be argued to have contributed to the entry of MSF and the engagement in partnerships to ensure a roll-out of a local treatment programme. The only way MSF could get involved in implementing their model for an HIV/AIDS programme was to engage in a partnership with the local authorities (in this regard the DoH). Simultaneously, they needed a civil society actor to perform the social mobilisation of the community in order to make people access the programme. As they were already engaged in a partnership with TAC which had been successful in Khayelitsha, they were keen to bring the organisation along to perform a similar role in Lusikisiki. However, TAC national already had a problematic relation with the national DoH.

The arena

The arena linking the four actors together is first and foremost the 12 primary health care clinics and secondly the St. Elizabeth Hospital. Whilst the clinics are managed by the local DoH, the hospital is run by the provincial DoH. These public institutions is the arena in which the programme has been implemented, thus all partners operate in, around or in relation to the clinics. The clinics face a number of challenges in the context of the programme. Some of the challenges the nurses and counsellors mentioned in the interviews were lack of staff (particularly doctors), drug shortages (though there has been no shortage of ARVs so far), lack of community participation due to cultural beliefs and traditional medicine, lack of formula milk for the PMTCT, no accommodation for new nurses, and lack of test kits, stationary and transport.

The local DoH are managing the clinics and employing the staff. MSF was providing expertise, training and medical aid to the clinics and originally acted as manager of the HIV/AIDS programme. MSF provided the ARVs for the first year until the Lusikisiki clinics were accredited as ARV sites, opening up for state provision of the drugs (MSF 2005). TACs role was doing the social mobilisation and promotion of treatment literacy in and around the clinics. Hence they built up local branches in the area, including one branch located by every clinic (MSF 2005).

The partnerships

The three central actors in the Lusikisiki programme had different reasons and agendas for engaging in partnerships. The external actor, MSF, had an interest in proving their capacity to roll out treatment in a rural area. The state actor, DoH, had been under fierce criticism both nationally and internationally due to their reluctance to provide universal access to treatment and was thus keen to prove their ability to implement and manage a treatment programme. On the other hand, TAC had an agenda of achieving universal access to treatment for PLWHA, which had previously led them into conflict with the national DoH. Despite their different nature, reasons and means for implementing the Lusikisiki HIV/AIDS programme, they had a common interest; to make the programme work.

MSF initiated the Lusikisiki HIV/AIDS programme in late 2002, after consulting with the provincial DoH (MSF and DoH 2006). They then agreed to collaborate on a treatment programme and Lusikisiki was chosen as the site for implementation due to its 'deep' rural character and a high HIV prevalence (MSF 2003, MSF and DoH 2006). MSF later signed a memorandum of understanding with the EC DoH and handed over a project proposal in early 2003. In this document MSF committed to providing ARVs for at least five years and to work hard for enabling the DoH to manage the programme and sustain the provision of the drugs. The programme was intended to be gradually taken over by the EC DoH. According to the project proposal, through MSF, TAC was to be a major role-player in assuring community involvement in the programme and in promoting access to treatment in the Eastern Cape (MSF 2003).

MSF spent the first months training local health workers, the local DoH and civil society actors in preparing for an actual implementation of the treatment programme. MSF taught the public health sector about the virus and its impacts, trained them on how to manage and initiate ARVs, and how to run the programme in their clinics. They employed doctors and nurses to work for MSF in Lusikisiki. Simultaneously, they employed and trained people from Lusikisiki and the nearby areas as adherence counsellors, pharmacy assistants or for administrative tasks and logistics (MSF and DoH 2006).[13]

[13] Interview MSF 14.02.07

In 2003, the South African government had finally committed to rolling out ARVs and a national plan for the roll-out of such was commissioned. Resulting from MSFs several months of training, the clinics were ready to start providing the treatment. In November 2003, there was a local ceremony featuring Nelson Mandela marking the official launch of the programme. Treatment roll-out begun in Lusikisiki (MSF and DoH 2006).

MSF was managing the programme for the first four years. They provided drugs and support to the clinics, employed and placed adherence counsellors in each clinic and deployed a mobile team including doctors to deal with the overall supervision and monitoring of the programme in the clinics. With the help of NMF they financed most activities related to the programme, both in the clinics and the communities through the funding of civil society actors as TAC. The programme experienced a gradual hand-over of the management until late 2006, when the DoH formally took over all responsibilities of the programme (MSF and DoH 2006).[14] In other words, the Lusikisiki HIV/AIDS programme has undergone a transformation from being an NGO-initiated pilot to a government-run programme.

MSF has been partnering with TAC since the implementation of the Khayelitsha HIV/AIDS programme in 2000 (MSF 2007b):

> Coupled to all MSF's clinical interventions is a strong community component implemented in partnership with the Treatment Action Campaign (TAC). TAC volunteers provide intense community education about HIV/AIDS, developing treatment literacy and generating greater awareness about available support and the rights of persons living with HIV (MSF 2007b:1).

Robins (2004a) argues that part of the TAC strategy has been networking with global civil society organisations such as the MSF. In Lusikisiki, they have been cooperating since the initiation of the HIV/AIDS programme. The partnership with MSF has been largely strategic for TAC also in the case of Lusikisiki. As MSF can be regarded as a powerful and influential external actor that enjoys a large extent of respect for its work internationally, partnering with MSF provides several advantages for TAC, both financially as well as in terms of publicity and opening up of opportunities for influence and participation in Lusikisiki. Support from a powerful and internationally recognised actor could then be important for national recognition as well as creating wider international support for their cause.

[14] Interview MSF 14.02.07

And according to Robins (2004b), TAC has been a strategic partner for MSF. Firstly, TAC provided the external agent with a link and entry point to the communities, as most of the TAC members had grown up or were living in these communities themselves. Hence, certain tasks that were not feasible for an external (foreign) actor to perform, such as community mobilisation and peer education, were made the responsibility of TAC. Secondly, bringing TAC to the programme added a pressure component on local government, as TAC could engage in 'toyitoying'[15] if the government refrained from some of its responsibilities.[16] If MSF had performed such activist tasks, it could have jeopardized their relation with the DoH.[17] Thirdly, partnering with TAC in Lusikisiki opened up opportunities for MSF to impact on policy at a national level. "TAC has loads of connections with the provinical level DoH. Then imagine how much they have with DoH at a national level?"[18]

My informants in TAC confirmed that it was in fact MSF who initiated the establishment of a local TAC office in Lusikisiki. The partnership in Khayelitsha had produced good results and they wished to have a similar partnership in the Lusikisiki context. MSF can be perceived both as a partner and a donor for TAC in Lusikisiki, as they were also the sole funder of the organisation from its establishment in the area. Simultaneously, they were engaged in workshops and trainings to empower local TAC members to perform their role in the programme.[19]

However, it can be argued that MSFs push for the establishment of a TAC office in Lusikisiki created a context for conflict with the local Department of Health (DoH), as it brought the culture of rights-based activism experienced on the national level. Although my informants acknowledged that there is cooperation between the DoH and TAC, they did not consider their relation to be an actual partnership. This was also confirmed by a informant related to the EC DoH. They know they have to deal with TAC, but they do not consider them to be one of their partners.[20] Still, TAC considered themselves one of the main partners in the programme. And both the local DoH informants recognised the importance of having a

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[15] 'Toyitoying' is a word used in South Africa for activism similar to 'protest' or 'demonstration' (according to my TAC informants), which has close links to the anti-apartheid movement (Marinovich and Silva 2000). I have chosen to employ the use of the word in its original form as this is the word used by my all my informants and a word that they relate to.
[16] Interview MSF 14.02.07
[17] Interview EC TAC 1 19.03.07
[18] Interview MSF 14.02.07
[19] Interview TAC 1 24.03.07, interview Adherence Counsellor 1 05.03.07
[20] Interview EC Socio-Economic Council 16.03.07

partnership with TAC, and that they are very much dependent upon the participation of civil society actors such as TAC if the programme is to succeed in the future.

> They assist us a lot. And when you go to the clinics and the locations doing these campaigns, you can literally see that there is a lot of work that they have done to the community. For instance, the communities now are so knowledgeable. And we would not do it alone as the Department of Health. We just couldn't do it alone...We appreciate the existence of TAC, because they are doing a lot for the community.[21]

This supports the argument of Mogale (2003), that if local governments are to promote development of a certain area of the community, they need to engage in partnerships with the actors that have the potential of contributing to the development of that particular area. In order to access the communities, they needed a civil society actor such as TAC.

However, there have been numerous challenges in the relation between the DoH and TAC also on the local level. For instance, the local DoH is often constrained by a politics of scale, where they rely on the provincial or national DoH in decision-making and delivery of services. Hence, there is a need to investigate the politics causing implications for the cooperation and partnerships.

Challenges to cooperation

The remaining part of the chapter is concerned with some of the implications related to the governance of treatment. The challenges to cooperation in Lusikisiki, seen through implications related to decentralisation, a dual state and the role individuals, increasing publicity, battles over responsibility and donor-recipient relations, are illustrative of the politics of governance operating on various geographical scales, ultimately shaping the programme and governance of treatment in Lusikisiki.

Decentralisation and politics of scale – The DoH hierarchy

Tensions between the national, provincial and local governments over HIV/AIDS policies, programmes and finances have been damaging for implementation of programmes in South Africa (Van der Vliet 2004). Such scalar transformations of power impact on the politics of

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[21] Interview DoH Lusikisiki 2 25.03.07

governance as indicated in the theoretical framework. Hence, partnerships and power struggles that take place on various geographical scales needs to be taken into account when researching impacts on local governance. This is no less the case of Lusikisiki, where power struggles take place between and within the various levels of the DoH. The DoH in Lusikisiki is vertically connected to the DoH in the District, province and nationally. On the other hand, they are horizontally connected to civil society.

As discussed in the theoretical framework, decentralisation has been intended to distribute some of the power and decision-making to lower scales of government, thus encouraging local participation in policy making and implementation of development initiatives. However, this is to a large extent not the case of Lusikisiki. Despite extensive decentralisation efforts, there seems to be limited autonomy in decision-making at the local level. Even if they listen to the demands placed by the civil society actors, for instance task shifting and formal integration of adherence counsellors in the programme, they do not have the authority to act on these demands.[22] They are in many ways reduced to being a medium for higher levels of government, and are only left with the responsibility for the implementation of the programmes in the 12 clinics.

In Lusikisiki, it appears that the local DoH is severely limited in its autonomy and space for decision-making due to regulations and restrictions placed upon them by the provincial and national DoH. Significant barriers to the sustainability of the programme are created on a higher level of government, leaving local government without the space to interfere. Policies at the national level can at the moment be seen as one of the main bottlenecks in the programme (MSF 2006). This is coupled with challenges related to the division of management and authority between the local and provincial DoH. For instance, the hospital is managed by the provincial DoH, whilst the 12 clinics which have implemented the programme fall under the authority of the local DoH. However, the local DoH's power over policies and larger structural issues affecting the clinics are practically non-existent. They are liable for employment in the clinics, but they do not have the power to create positions in the clinics which have not been formalised by higher levels of government.[23] Simultaneously, according to the MSF informant[24] and Beresford (2004), there are several challenges related

[22] Interview DoH Lusikisiki 1 14.03.07, interview DoH Lusikisiki 2 25.03.07
[23] Interview MSF 14.02.07, interview DoH Lusikisiki 1 14.03.07
[24] Interview MSF 14.02.07

to the management of the programme, as the provincial and local DoH have gaps in the communication and coordination of the hospital and the clinics. The work has not been properly coordinated between these two levels of government and MSF:

> We need a comprehensive approach to management…The fact that we have a provincial hospital and a district clinic, brings the two authorities to have to sit at a table and have to discuss how we are going to do about it. Because the patients don't care whether services are from province or district office, but if they could be referred to the hospital, then I need a good result to come back to the clinic…We need to be talking to one another. [25]

Lack of communication between the local and provincial DoH and the formers limited autonomy also presented challenges to the cooperation with TAC. All local TAC informants argued that they always have to collect permission from the provincial DoH in order to gain consent from the local DoH to carry out activities or events in Lusikisiki. It was considered one of the main constraints to carry out their tasks in the programme.

It has also been argued that "the lack of leadership at the provincial administration...in the EC are seriously obstructing the implementation of the Constitutional Court resolution" to roll out ARVs (MSF 2003:4). Nevertheless, it can be argued that the permission given by the EC DoH to an external actor to start the implementation of a local HIV/AIDS treatment programme before the launch of a national plan to roll out ARVs, illustrated a political will to roll out treatment in the Eastern Cape Province that had not yet been seen at the national level.

The dual state and the role of individuals

As argued by Camay and Gordon (2004), the space opened up for popular participation, is not always determined by Constitutional laws and regulations. It also depends on the tone set by local government officials. Unless local government has the capacity or is willing to listen to the local stakeholders, popular participation through decentralisation can not be realised.

As mentioned above, TAC in Lusikisiki complained that they were having problems accessing information and communicating with employees in the local DoH. Most informants implied that it was to a large extent due to the unwillingness of certain leading individuals in the department to cooperate and communicate with civil society actors. Simultaneously MSF

[25] Interview MSF 14.02.07

said that the local DoH had initially welcomed the programme, but that they eventually became a bit resistant, due to "issues of egos and personality" playing a role in the local DoH.[26] According to Beresford (2004:288), "too often the inability, or lack of interest, of local level officials seem to be disregarded or overlooked" by the national leadership. Even the two informants in the local DoH recognised the difficulty of working with the leadership in their department. They were afraid of the consequences if they communicated or cooperated with other stakeholders in the programme without authorisation to do so from their superiors. However, the DoH is divided with regards to cooperation with civil society actors. Both informants in the local DoH recognised and emphasised the need for cooperating with local civil society actors, such as TAC.

Hence, even within the DoH in Lusikisiki, there are numerous different actors operating. To a certain extent we could say that the DoH is not one unified, but many actors. Individuals within the Department seem to have different opinions regarding civil society actors and operate with different rules that impact on the work and relations in various ways.

Also within the Eastern Cape DoH, individuals seemed to have a large impact on the shape of governance and participation. Individual relations have shaped both relations and the space for TAC and MSF. According to MSF:

> There was basically one person who was very supportive from the very beginning and she fought very hard to make the programme happen, and so she deserves most of the credit in allowing that to happen...But she is one person...She's got the legislation that she has basically.[27]

Simultaneously, one of the central managers in relation to the programme expressed close relations with MSF, but was rather ambivalent regarding the role of and relation with TAC.[28] The perceptions and ambivalence towards TAC was later attempted explained by a central TAC representative in the province. Prior to their engagements as respectively a DoH and a TAC manager, they had been working parallel on a different project, where the now TAC representative had caused several problems for the now DoH representative's work. As their relationship had been conflictual in the past, when they became central representatives of DoH and TAC, the past conflict between the two became the cause of the problems of

[26] Interview MSF 14.02.07
[27] Interview MSF 14.02.07
[28] Interview EC DoH 20.03.07

cooperation experienced in their new jobs.[29] Hence, there was anticipation as to what extent it would lead to changes in cooperation if either of them were to leave their position. One of my informants suggested that the removal of either could radically change and improve the character of communication and cooperation between the DoH and TAC in the province.[30]

Neither the cooperation between MSF and the DoH has been without a hitch. The informant in MSF argued that their role in Lusikisiki was challenging due to a difficult relation with central individuals within the DoH.[31] One informant connected to the EC DoH said people within the DoH had called the programme an 'umhlungu' (white) programme.[32] Hence there is a question of whether the entry of an external agent with white people in the leadership could have generated some negative attitudes towards the programme and cooperation. It should not be ignored that South Africa is a country with a long history of apartheid, where the black majority in the population was ruled by a white minority (Habib and Kotzé 2003). Simultaneously, Dr Hermann Reuter claimed that "officials tend to take us as a threat to them" (Reuter quoted in Beresford 2004:287). This was also confirmed by the informants within the CSOs in Lusikisiki, arguing that the DoH had felt threatened by the entry of MSF in Lusikisiki. They felt that the presence of MSF questioned both their authority and their capacity to provide access to health care in the context of HIV/AIDS. MSF pushed forward the implementation of a model that they had designed which radically altered local clinic structure. They also temporarily removed some of the authority the local DoH otherwise enjoys in their clinics, as MSF was initially managing the programme.

Some of the challenges to cooperation in Lusikisiki can be explained by picking up on Migdal's arguments. According to Migdal (2001), the state is of dual character, because it is in one setting operating as a single actor whilst in another setting it is influenced by and cooperating with various civil society actors. Simultaneously, it is often split in groupings within the state working for different interests, engaging in coalitions or collaborations with various actors within society and within the state. In many ways, this theoretical argument is illustrative of what happens in Lusikisiki. On the one hand, the DoH operates as a single actor in managing the programme. On the other hand, the DoH is split between differing interests, individuals and groups. Both the state as a single actor and the state as a number of groups

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[29] Interview EC TAC 3 31.03.07
[30] Interview academic source 30.03.07
[31] Interview MSF 14.02.07
[32] Interview EC Socio-Economic Council 16.03.07

and individuals are cooperating or in conflict with various civil society actors. However, the case of Lusikisiki and the DoH seems to be more a question of power-relations between individuals than of the state as a unified actor in relation to civil society actors. The shape that governance has taken in Lusikisiki has to a certain extent been a result of perceptions and relations both within the state agency and in between various state and civil society actors.

'All eyes on Lusikisiki'

As indicated above, bottlenecks to the Lusikisiki programme is not necessarily resulting from a lack of political will with the managers in the DoH at a local level. They rather seem to be frustrated by bureaucracy and having to work within restricted frames of governance. The existing division of power and decision-making limits their work and capacity. Within such a context, they are also feeling the pressure not just from the provincial but the national level. As the Lusikisiki programme has increasingly become known as a role model in South Africa and the region, the amount of pressure on the local DoH is escalating. The local DoH officials are well aware that if they make any mistakes, they are in a vulnerable position. They seem to believe that a programme failure will have grave consequences, whether it is with concern to negative publicity or their own position in the programme.

Because of the amount of publicity that the programme has gotten nationally, the local DoH managers have been invited to attend meetings and done presentations at conferences around the country.[33] Hence, it becomes increasingly important for the local DoH that the programme receives good reviews and that it does not fail.

> We are interested in the department with time to be recognised and become a benchmark for the programme...nationally...Once you say that you are from Lusikisiki and working for the programme, you are told 'Ey! You are working hard there!'...People are asking you when you say you are from Lusikisiki. You have to work.[34]

The increasing focus and publicity on the programme on a national level can perhaps explain some of the reception of TACs activism and 'toyitoying' by the local DoH. This may lead to a negative publicity as it makes it seem as if there is dissatisfaction with the programme and that the DoH is not doing their job sufficiently. It can thus explain why the DoH attempts to silence the activism and 'toyitoying' by withholding information from the more critical voices

[33] Interview DoH Lusikisiki 1 14.03.07, interview DoH Lusikisiki 2 25.03.07
[34] Interview DoH Lusikisiki 1 14.03.02

in the area. Such a withholding of information poses clear challenges to TAC performing its role in the programme. However they have found ways of coping with it, as will be discussed later in the analysis.

A battle about responsibility

According to one of my informants, there is a lack of responsibility taken for the programme and changes. Whenever something goes wrong or aspects of the programme are criticised, the government representatives disclaim of liability, rather blaming others for the faults.[35] The responsibility of the programme was originally intended to be divided between MSF and the DoH. The DoH was for instance responsible for the provision of drugs and formula milk to the clinics (Beresford 2004). The case of provision of formula milk for the PMTCT provides a good example of how there was a battle about responsibility between the two. According to my informants in the Lusikisiki clinics, they were and are often short of formula milk. Despite repeated promises from the DoH that formula milk would be provided, it failed to turn up. If a breastfeeding HIV-positive mother does not get the formula milk, the chances are that she will breastfeed the baby. Hence MSF would feel pressured to buy formula milk for the clinics, even though it is not supposed to be their responsibility. And "as long as the aid agency supplies the formula, local government doesn't appear too concerned about getting its act together to provide the formula" (Beresford 2004:281). There is thus a need for a pressure component in the programme, ensuring successful implementation and management. However, MSF has identified a possible solution to the inaction and lack of responsibility taken. "MSF recognises that that the most effective way to boot local administrators into action is to mobilise the community" (Beresford 2004:281). This is precisely the role that TAC has been assigned. According to Robins (2004b:3), "the emergence of TAC as a grassroots based social movement created the conditions for MSF's empowering vision of health citizenship". The role played by TAC is thus a central theme for the coming chapter of the analysis.

Donor-recipient challenges to cooperation

The MSF funding of TAC created certain issues for TAC at the time they were working together in Lusikisiki. According to one of my informants,[36] there was at times a serious lack of communication between the two organisations with regards to events and activities being

[35] Interview MSF 14.02.07
[36] Interview EC TAC 3 30.03.07

held. It can partly be explained by a lack of integrating each other properly in the planning process. Instead of planning activities together or dividing the responsibility, they had parallel activities to each other. There were cases where TAC would discover that they were planning events on the same day, and because TAC was needed in the MSF event and MSF was their funder, they had to discard their own activities. The loyalty lies with MSF as they are the ones funding their activities.[37] This supports the argument made in the theoretical chapter that recipients of aid have limited impact on setting the agenda (Jones 2004a). If TAC has to change or discard its activities because of MSF, their accountability becomes directed upwards rather than downwards to the grassroots.

Despite there being little actual conditionality from the donor (MSF) regarding the use of funds, TAC felt it was expected that they participate in the activities designed and promoted by MSF.[38] Hence, the partnership between MSF and TAC has been somewhat vertical as the agenda has largely been set by the donor. The fact that MSF considers TAC a partner implies a horizontal relation between the two. However, the case of Lusikisiki illustrates that the inequalities in power balances between donor and recipient can not easily be altered as long as only one partner possesses the financial resources.

Nevertheless, it can be argued that the case of TAC in Lusikisiki does not support the argument that the NGOs tailor activities and funding proposals to match the agenda of donors, as discussed in the theoretical framework. Due to TAC in Lusikisiki having strong links to national and provincial offices, they have pursued their organisation's interests also in Lusikisiki with its distinctive agenda and means for realising this, which will be seen in the coming chapter. And fortunately, MSF in Lusikisiki had more of an activist nature than other TAC donors, as the MSF head in Lusikisiki was a TAC activist and member himself. Hence, there was also space for the use of funds for activist purposes, and both of TACs 'two faces' were thus able to be integrated in the programme.

On the contrary, the Eastern Cape TAC has experienced donor conditionality with the funding. Some donors have argued for TAC to pursue less of an activist role and be more of a service-delivery provider. For instance, two of my informants argued that one of the main donors of the provincial TAC refuses to fund the activist side of TAC and insists its funds

[37] Interview TAC 1 24.03.07
[38] Interview TAC 1 24.03.07

should only be used for service-delivery. Simultaneously, they have argued for TAC to be less confrontational and more cooperative in their approach.[39] Hence, the provincial TACs activities are being limited by the donor's agenda. This could affect the activities of TAC in Lusikisiki, if their funding starts coming from the province when the financial support from MSF terminates.

Concluding remarks

As discussed in the theoretical framework, the structure of governance is a result of a process of interaction between various groups. This interaction can thus be seen as central to the politics of governance. In Lusikisiki, the politics of governance in the context of HIV/AIDS has largely been played out within and between MSF, TAC and the DoH. And as Migdal (2001) argues, 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 is no less the case of Lusikisiki. The three central partners in the programme belong to three different set of actors; one international NGO, one national NGO and one state department. Hence, they came into the collaboration with different strengths and limitations, varying set of agendas and means to achieve such. This will also be elaborated on in the coming chapters of the analysis.

The rationality underpinning the initiation of the Lusikisiki HIV/AIDS programme can be explained by a few central factors. Firstly, there was a changing political climate in the context of HIV/AIDS and a new national plan for the roll-out of ARVs was in process. Secondly, MSF managed to attract the support of Nelson Mandela, which opened up political space and provided them with what they called a 'political shield' for their pilot programme. Thirdly, 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 such. They thus based their new programme on a successful urban model.

The provincial DoH was keen to prove that they could successfully implement and manage such a programme. As the South African DoH had been under fierce criticism both nationally and internationally for its reluctance to provide its people with universal access to ARVs, the

[39] Interview EC TAC 3 30.03.07, interview academic informant 31.03.07

amount of pressure and expectations connected to the Lusikisiki programme was high. It is particularly the local DoH which is feeling the pressure from its superior departments not to fail in the management of this programme. However, their space and autonomy with regards to the programme is being limited by policies and regulations coming from higher levels of the department.

The role of power relations has a central place in the politics of governance, where various individuals or groups may attempt to impact on policies to make them fit their own agenda. Also in Lusikisiki there is an ongoing power-play both within the state agency and in between the state and other actors. Even if MSF and DoH cooperated on implementing the programme, there is a division within the department between those who were positive and those who were reluctant to the collaboration with MSF in Lusikisiki. There are central individuals who disapprove of MSFs involvement and feel their authority threatened by their presence and attempts to alter the local health care structures. Simultaneously, there is a division within the DoH between those who emphasise the need for cooperation with TAC and those who block them from accessing crucial information for performing their role in the programme.

In other words, the role of individuals and divisions within both the local and provincial DoH has had an impact on the shaping of the programme and partner-relations. This supports the arguments made in the theoretical framework of a dual state and also that degrees of participation in local governance could depend on the attitudes of local government officials. Hence the shape that governance takes will depend on the context in which it evolves.

Furthermore, this chapter has illustrated a transition from the politics to the governance of treatment, as seen in the case of Lusikisiki. Different actors with an interest in the local governance of treatment with ARVs approached each other and started a dialogue which led to the engagement in partnerships to ensure the implementation and management of a local treatment programme. The shift from a focus on the politics to the governance of treatment has presented the programme and partners with a range of new challenges. After the launch of a new national plan including treatment for HIV/AIDS and the initiation of the programme, "for MSF the problem was no longer that of challenging government over AIDS policies, but rather applying pressure on the health service to ensure that treatment policy was implemented properly" (Robins 2004b:2). There was a need to add a pressure component to ensure the successful governance of the programme. This role has largely been assigned to the

civil society actor TAC. Their role in the politics and governance of the programme is thus a central theme of the following chapter of the analysis.

5. SOCIAL MOBILISATION AND THE DUAL ROLE OF THE TREATMENT ACTION CAMPAIGN

The theoretical framework of this thesis argued that civil society organisations are diverse and that organisations are characterised by politics of engagement or politics of opposition in their relations to the state. Simultaneously, such a divide is not rigid and it can be necessary to combine engagement with opposition in order to ensure the rights and the service-delivery to marginalised populations.

This second chapter of the analysis shapes the answer to the second research question of this thesis regarding the role of and impact of civil society actors on the programme and collaboration. Central to this chapter is the social mobilisation and treatment literacy in the Lusikisiki HIV/AIDS programme. As the bulk of this task has been assigned to TAC, this chapter will primarily be revolving around TAC activities and challenges. However, TAC has played a dual role in their social mobilisation, as it has not only been directed towards service-delivery but also towards the rights and politics of health. Furthermore, the rights-based approach they employed in mobilisations has impacted on their relations with the DoH. TAC can be argued to be a civil society organisation which has combined politics of engagement with politics of opposition, as outlined in the theoretical framework.

In this chapter, I will first look at the role of social mobilisation in the programme, followed by an investigation of the role of TAC. Secondly, I will analyse some of the challenges related to the social mobilisation as performed by TAC in Lusikisiki. The chapter ends with a discussion of how TAC has played a dual role in Lusikisiki, through what I call ‘the TAC politics of mobilisation’.

The role of social mobilisation in the programme

As argued in the introduction chapter, South African leaders’ AIDS ‘denialism’ fuelled the stigma and confusion around HIV/AIDS in South Africa and led people to believe for instance that ARVs are toxic. This thus calls for an extensive social mobilisation to reverse some of the misconceptions and stigma around HIV/AIDS if a treatment programme is to succeed. And according to Robins (2004a), AIDS myths, ‘denialism’ and stigma are frequent

in rural South African communities that have not been exposed to grassroots mobilisation, treatment literacy campaigns and AIDS activism. In other words, in order to successfully roll out treatment in a rural area, these barriers have to be overcome. Hence for the Lusikisiki HIV/AIDS programme, one of the basic tasks that needed to be performed was a social mobilisation of the affected communities. Social mobilisation can be used to inform people about the actions that are to take place, promote acceptance of the programme and encourage people to come to the clinics to get tested and treated (TAC 2006). Simultaneously the social mobilisation has educated people about their rights and created openness and knowledge around HIV/AIDS. It has furthermore contributed to a higher level of treatment literacy, central to the success of a treatment programme.[40] One adherence counsellor said that:

> At the beginning people were scared to take ARVs, and they believed that when they are sick they will die...at least now...we don't take much time preparing people for ARVs when we are preparing them, because they know. So it is helping, because most of the people are willing to take ARVs...because they know the side-effects and all those things.[41]

The social mobilisation has been carried out in the surrounding communities as well as in clinics, churches and schools. In the clinics, counsellors as well as TAC educated people about treatment. Also support groups (typically led by a TAC member) have been a central arena for promoting treatment literacy for the people who have recently been diagnosed with HIV.[42]

Promoting treatment literacy

The quote above illustrates a change in the perceptions of ARVs in Lusikisiki. Whilst people were scared of taking ARVs in the beginning, the perceptions of the drug has gradually changed during the course of the programme. And the promotion of treatment literacy has been a central part of the social mobilisation in Lusikisiki. The term treatment literacy refers to 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 more responsible for their own care and will demand their rights when proper care is not available to them" (TAC 2006:101). In other words, treatment literacy is concerned with advocacy; it is about educating people about treatment and their rights to it. 'Treatment literacy' is in this thesis

[40] Interview TAC 4 13.03.07, interview TAC 2 24.03.07, interview TAC 1 24.03.07.
[41] Interview Adherence Counsellor 3 14.03.07
[42] Interview Adherence Counsellor 1 05.03.07, informal talks with TAC Lusikisiki members

taken to be treatment literacy in the context of HIV/AIDS and related illnesses or diseases. TACs "Treatment Literacy Campaign...aims to make information that could help save lives accessible to people living with HIV and their communities" (TAC 2006:V).

In Lusikisiki, people were lacking knowledge about medical treatment for HIV/AIDS and opportunistic infections[43] prior to the introduction of the programme. ARVs were previously not accessible in the public health sector in Lusikisiki. Most of the primary health care clinics were not even in possession of the drugs that are placed on the South African Essential Drug List. Yet, with the introduction of the programme, treatment for opportunistic infections and ARVs became available at all 12 primary health care clinics (MSF and DoH 2006). And despite the former lack of knowledge of treatment locally, people are now starting to know the different types of treatment available, and according to most of my informants; a lot of people are starting to demand their rights to treatment.[44] The example of shingles[45] illustrates this.

Prior to the introduction of the programme, if someone got shingles, they would typically be given the drug 'calamine'. However, 'acyclovir' is known as a more effective drug for this particular condition. Consequently, TAC and others in Lusikisiki started campaigning and informing people about their rights to acyclovir. This has led to a change in the medication used for shingles in Lusikisiki today, according to my informants. If people in Lusikisiki get shingles today, s/he knows they are entitled to get acyclovir and a lot of people demand to get it when they go to the clinics.

Robins (2004a:669) 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 mobilisation and health activism". These obstacles have to a large extent been broken down in Lusikisiki, precisely as a result of the social mobilisation of the community. According to my informants, the treatment literacy campaigns have taught people about the available drugs as well as their rights to these drugs. And as argued above, in some cases the Lusikisiki community has started demanding these rights in the clinics.

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[43] Opportunistic infections are infections which can occur with people with a poorly functioning or suppressed immune system, for instance people living with HIV (Henriksen 2006).
[44] Interview TAC 3 25.03.07, interview TAC 1 24.03.07,interview Adherence Counsellor 1 05.03.07
[45] Shingles is caused by a virus creating groups of painful blisters on the surface of the skin (Encyclopaedia Britannica Online 2007).

The treatment literacy campaigns and community mobilisation appears to have been central and crucial to the success of the HIV/AIDS programme. Prior to the introduction of the HIV/AIDS programme in Lusikisiki, the knowledge about HIV/AIDS was minimal. There was no organised psycho-social support, no hope for people living with HIV. However, during the first three years of the programme close to two-thirds of the adult population did Voluntary Counselling and Testing (VCT)[46] (though some may be duplicates), and 2200 people were receiving ARVs in late 2006 (MSF and DoH 2006).[47] All my informants expressed that the access to ARVs, mobilisation and treatment literacy work has been of major importance in turning HIV from being a death sentence to positive living (Robins 2004b). One informant was diagnosed with HIV in Lusikisiki before the introduction of the programme:

> Even the doctor said, if you are HIV-positive, you must go and die. Because there is nothing to help you...There was no treatment for HIV, that is why they say these things...All the people knew that if they tested positive, they must just go and die.[48]

As I only collected information from the partners of the programme, not the patients nor the general population in Lusikisiki, it is hard to estimate to what extent there is treatment literacy in Lusikisiki. However, it seems that the mobilisation of the community through treatment literacy campaigns have led to changes in knowledge about treatment and HIV/AIDS in the area. The majority of my informants believed that there is a high level of treatment literacy in the area, at a minimum in relation to the situation prior to the introduction of the programme, when the term 'treatment literacy' was definitely not part of the local vocabulary.

The role of TAC

TAC is known nationally for their campaigns for treatment for People Living With HIV/AIDS (PLWHA), employing means and modes such as demonstrations, t-shirts and promotion of treatment literacy (Friedman and Mottiar 2004, Robins 2004a, TAC 2006). In Lusikisiki, the bulk of the social mobilisation in the programme has been assigned to TAC. MSF brought

[46] The high number of people who had done VCT can not solely be accredited to the social mobilisation. It is likely to also have been a consequence of decentralising VCT from the hospital to the clinic-level. Hence, from the introduction of the programme, people were able to access VCT at their primary health care clinic.
[47] Interview DoH Lusikisiki 2 25.03.07
[48] Interview TAC 4 13.03.07

TAC to Lusikisiki to lead the efforts of mobilising the communities and also the DoH says they rely to a large extent on TAC to perform this mobilisation.[49] All but one of my informants working in the clinics accredited most of the treatment literacy success to TAC.

Mode and means of mobilisation

TAC has done workshops and trained Treatment Literacy Practitioners (TLPs) and other volunteers to educate and mobilise the Lusikisiki communities. Central to their approach and the programme is the disclosure of HIV status breaking down barriers of stigma in the communities. Both TAC members and other people in the community are encouraged to be open about living with HIV/AIDS (MSF and DoH 2006).[50] TAC regularly goes into the communities to create awareness around central issues or events. They do community marches and door-to-door action. They frequently visit schools, clinics, churches and other institutions in the community. One large event that took place in March 2007 was TACs community mobilisations to prepare and advocate for a public dialogue they arranged on the new South African National Strategic Plan (NSP) on HIV/AIDS. The mobilisation took place in schools, clinics, a tea plantation, and selected villages over a three days period intended to encourage the community to participate in the dialogue comprising both civil society actors and government representatives.[51]

The community marches were often carried out through organising a group of TAC members to go out to the community in question. They would march through the communities, sing songs with lyrics related to HIV/AIDS, and whenever people approached them they would stop and have a quick chat. They do attract a lot of attention as a group of people singing and marching along roads in what are normally quiet rural communities.[52]

TACs social mobilisation can be seen as not just a way of bringing out information and mobilising the communities. The time spent in the communities, particularly through door-to-door action, also brings them closer to the realities of the people they aim to assist. It sustains their grassroots relations as people become familiar with the organisation, its aims and objectives. The means they use for social mobilisation (such as door-to-door action) provide

[49] Interview DoH Lusikisiki 2 25.03.07
[50] Interview MSF 14.02.07
[51] My observations
[52] My observations

TAC with news and information about challenges in the targeted communities, as well as a familiar name in the area.

Other means of mobilisation

One of TACs most distributed and publicly visible items is the t-shirt featuring the text 'HIV positive'. The abundance of these t-shirts seen around Lusikisiki is striking (Robins 2004b). I experienced going to community mobilisations with TAC in the uttermost rural parts of Lusikisiki and seemingly out of nowhere people would appear with these t-shirts. It is hard to tell whether this actually is an indication of a low level of stigma towards PLWHA, a strong TAC support base or if it simply means that TAC and MSF mass-produced and handed out the t-shirts in a rural area where there is a high level of poverty and people are more than happy to accept free t-shirts. Nevertheless, some of my interviews indicated that there is in fact a decreasing level of stigma and a high acceptance of the HIV/AIDS programme, much as a result of the community mobilisation. One informant explains the difference between wearing this t-shirt in one of the largest cities in the province versus wearing it in Lusikisiki:

> I normally go down to East London. If I go there wearing the HIV positive t-shirt I've got looks from people...Here they don't recognise 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 recognise 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 on 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.[53]

In other words, there is a difference in people's reactions when wearing a t-shirt with the inscription 'HIV-positive' in the rural Lusikisiki and the urban East London, largely as a result of the social mobilisation in the Lusikisiki programme where people are now more knowledgeable and there is less stigma around HIV/AIDS.

Providing fellowship and advocacy

Nationally, TAC is known for being an organisation that provides a unity and sense of belong to people living with HIV/AIDS. It is an organisation not simply driven by interests, but also by identity (Friedman and Mottiar 2004, Robins 2004a). This also seems to be the case in

[53] Interview HAACO 2 07.03.07

Lusikisiki. Most informants within TAC emphasised the strength and hope that their organisation had provided them with. As many of them were HIV-positive themselves, what TAC offered was a feeling of unity and belonging, and meaning to life by helping other people in similar or worse situations.

> When I'm back from hospital, TAC came…So I got more 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.[54]

When members from the newly established TAC branches in Lusikisiki attended a TAC march in Cape Town in 2003, they came home motivated for a local struggle feeling that they were part of a national social movement. TAC has later adopted and translated national campaigns into local events (Robins 2004b).

TAC is also used for assistance by the people enrolled on the programme if they have problems accessing the treatment they know they have a right to get, as in the case of 'acyclovir'. If a clinic objects to giving out this particular type of treatment (it could be due to various causes, quite often shortage), the patient might approach TAC to sort it out.[55] During the time I spent at TAC Lusikisiki's office, this was something I experienced several times. TAC would then attempt to sort this out with the nurse at the clinic. Using TAC for claiming their rights or addressing their problems at the clinic seemed to be an easier way for many to avoid confrontations with the nurses at the clinics.

Relation with the community

What several of my interviews indicated and what the informant expressed above in relation to the t-shirts is not just that there is a decreasing stigma and that people have accepted the programme. The informant is also saying that the ARVs had a de-stigmatising effect on the community, because the community saw that people who were given ARVs recovered. Consequently, being diagnosed with HIV was no longer seen as a death sentence. However, TAC was experiencing challenges in their mobilisations because of the history of AIDS 'denialism' in South Africa, when for instance it was suggested by government that ARVs are toxic (Van der Vliet 2004). One informant talked about how TAC has changed the perceptions of ARVs in Lusikisiki through their strategy of disclosing their status:

[54] Interview TAC 4 13.03.07
[55] Interview TAC 3 25.03.07

> We know that ARVs 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 a challenge of the misleading information...it lead to our people not knowing who to believe. But they know now...'I've seen X is taking ARVs and is healthy'.[56]

When TAC was first established in Lusikisiki, they were not accepted in the community. The people did not understand the role that TAC aimed to play in Lusikisiki and they were to a large extent perceived as an anti-government organisation 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 toyitoying for our government?' But now they saw the change. They see that people in Lusikisiki are becoming right, they are fit, they are healthy...that the ARVs are helping their families.[57]

> People didn't know anything…People thought that TAC is coming to throw over the government...They think we are a political organisation and also that we are anti-government. But then we tried now to explain and explain, so that they can understand.[58]

Nevertheless, TAC has been working in the communities for more than four years now and the perception of the organisation appears to have changed. Even though people did not originally understand the reasons for the sudden appearance of the organisation in the area, people are increasingly aware of what the organisation represents and that they are not anti-government. According to my informants in TAC, the organisation now feels accepted and welcomed in Lusikisiki:

> They accept TAC now. And they also ask for TAC now. Things are not the same like last year. 'Cause they were not understanding about TAC. [59]

> The people of Lusikisiki they are very proud of TAC, because TAC is fighting for the rights of the people.[60]

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[56] Interview TAC 2 24.03.07. I have replaced a name with 'X' for anonymity reasons.
[57] Interview Adherence Counsellor 1 05.03.07
[58] Interview TAC 3 25.03.07
[59] Interview TAC 3 25.03.07
[60] Interview TAC 4 13.03.07

This was also confirmed by the informal conversations I had in the part of Lusikisiki I was staying in. Most people I asked were familiar with TAC and their mission. And people from the surrounding communities came to the office to ask for assistance in various challenges. Schoolchildren came for information for essays or their classes.[61] The people in the community I spoke to dedicated much of the honour for the change in perceptions and knowledge about HIV/AIDS in Lusikisiki to TAC. "HIV/AIDS is now treated like headache...because of TAC it is now headache."[62]

In summary, it can be argued that social mobilisation and promotion of treatment literacy is both a way for TAC to get closer to the communities they intend to serve as well as a way to build new perceptions and a local image of TAC as a friend of the community, assisting them in advocacy and service delivery, rather than as a political force challenging state power. Through their work in the community they do not only contribute to decrease stigma around HIV/AIDS, but are also removing the stigma against TAC.

Contributing to community empowerment?

Some of the local TAC informants also argued that through mobilisation they also attempt to empower the community, to inform them that they have a voice and an opportunity to impact on policy and local governance of HIV/AIDS. According to one informant:

> The people now know that they have a voice. 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.[63]

Most informants argued that the programme had changed the relations between the state and civil society in Lusikisiki. MSF argued that the community previously "had no reason to get together and fight for something in the environment...Then they got shaken up. It was an opportunity, I think, to bring people together."[64] In other words, the initiation of the programme created a context in which the community had a reason to unite over a common cause; the roll-out of ARVs. It can also be argued that TACs "grassroots participation...offers members an opportunity to become active citizens rather than passive subjects" (Friedman

[61] My observations.
[62] Informal talk with local woman 25.02.07
[63] Interview TAC 2 24.03.07
[64] Interview MSF 14.02.07

and Mottiar 2006:29). Through empowering citizens to participate in local governance of HIV/AIDS, TAC is simultaneously nursing and assisting in building local democracy.

Challenges to the social mobilisation

It has been argued that TAC has been driving a 'globalisation from below'. Their grassroots mobilisation has attracted international solidarity and support in their fight against the big pharmaceutical companies and making the South African government commit to rolling out ARVs. Their cause has straddled local, national and global spaces; hence partnerships have been engaged on all three scales (Robins 2004a). However, I also argue that their mobilisation has deployed a class-based politics and is somewhat gender biased. Furthermore, it can be debated to what extent TAC is in fact a grassroots, locally embedded organisation or whether it is driven by top-down relations and influence.

Politics of class

There was an indication of a difference in behaviour and stigma between illiterate and literate groups in Lusikisiki. Several informants confirmed that they knew people in high positions in Lusikisiki that were on ARVs, but were hiding their HIV-positive status. It appeared that the literate part of the population in Lusikisiki, such as teachers and nurses, were the ones that were afraid to disclose and discuss their status. Simultaneously, the illiterate part of the population in Lusikisiki seemed to be much more adaptable to the TAC messages and education, as they were the ones to disclose.[65] Why is this? Some might argue it can be due to illiterates being more adaptable to new messages and education in general, that their opinions can be more easily 'shaped' than those of the literate. On the other hand, it could simply be because TAC has to a large extent focused their messages on the illiterate part of the population and designed a community mobilisation and treatment literacy campaign which is mainly directed towards the poor and illiterate.

From my observations, I do believe there is some truth in the latter argument, as it seemed that TAC focused much more of their resources and time reaching out to people who were in the more marginalized layers of society. Some of my informants also confirmed that the people who are present in TACs workshops and gatherings, are generally unemployed and

[65] Interview HAACO 2 07.03.07

uneducated. Furthermore, TACs focus on mobilisation amongst the poor and marginalised is confirmed by a number of articles. According to Robins (2004a), TAC has deployed a class-based politics and are mainly mobilising amongst the poor and unemployed. Perhaps due to the predominantly urban character, location and membership base of TAC (Robins 2004a), little research has been conducted on TAC in rural areas. However, from my observations and interviews, there are similarities with the existing research on urban TAC and the case of Lusikisiki.

When carrying out community mobilisations in Lusikisiki during the day, you are likely to only encounter the unemployed (often women) or poor farmers as they are the only people likely to be staying around the house at such a time.[66] And taking a closer look at the TAC national membership base further illustrates the effects of this argument. The members are predominantly poor and black. Women outnumber men, young outnumber old and about 80% of members are unemployed and have low levels of education (Friedman and Mottiar 2004). In other words, TAC typically does not speak for the educated and employed, the people in upper or middle class in society. If TAC in Lusikisiki is perceived as an organisation for the poor and illiterate it could create barriers of communication and block a feeling of common identity with higher classes. If lower classes get tested and disclose, whilst middle- and upper class citizens do not get tested or keep their HIV-status private, it could generate a feeling of 'othering' of the epidemic, preventing some social classes from identifying HIV/AIDS as a problem affecting them. This could alter the apartheid views of HIV/AIDS as an epidemic of race (Robins 2004a), making it appear as an epidemic of class.

Nevertheless, a class-based mobilisation might be relevant in the context of Lusikisiki. As mentioned in the theoretical framework, there is often a large divide in the policy agenda of the elite and the grassroots. Furthermore, it is necessary that all groups are heard if there is to be participatory governance of HIV/AIDS. Hence there is a need to empower poor and marginalised groups on how to make use of their opportunities to influence on the process of decision-making. As illustrated above through promotion of treatment literacy and the public dialogue on the NSP, TACs mobilisation has the potential to contribute to this empowerment. One informant[67] argued that there needs to be more community participation in the making of policies. The lack of community participation thus creates a gap in the policy making around

[66] My observations
[67] Interview TAC 1 24.03.07

HIV/AIDS. Yet all groups in the community need to be participating already in the process of decision-making if participatory local governance is to be realised. TAC is contributing to the realisation of such governance in Lusikisiki through mobilising the traditionally marginalised parts of the community, empowering them through educating them about their rights and including them in events such as the public dialogue on the NSP. It can however be discussed to what extent the mobilisation preparing for the latter was successful, as it seemed there were not a large number of the people targeted in the mobilisation that showed up.[68] In other words, there may still be a need to mobilise and empower the community to exercise their rights of participation in governance. On the one hand, the community mobilisation has lead to an increasing knowledge and awareness around HIV/AIDS and treatment in Lusikisiki. On the other hand, ensuring community participation in the process of policy-making may still be a challenge that TAC and Lusikisiki have to face in the future.

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.[69]

It seems that it is first and foremost the women who disclose their HIV-positive status in Lusikisiki. So why are the men not disclosing? In line with Robins (2004a:670), I argue that "patriarchal attitudes are likely to continue to be serious obstacles to AIDS prevention and treatment programmes". As one informant puts it:

> 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 the 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.[70]

This indicates that patriarchal relations are still operating in Lusikisiki as was confirmed by some of the informants. There are still men with more than one wife, and if a man does not

[68] My observations and informal talks with TAC members
[69] Interview TAC 3 25.03.07
[70] Interview TAC 3 25.03.07

wish to use a condom, it is not likely to happen. TAC acknowledges that it is difficult working in rural areas where these views persist. According to Friedman and Mottiar (2004), another reason for men's reluctance to participate in such programmes may be that they are to a larger extent fearing the stigma of living as HIV-positive. Furthermore, the apparent female dominance of TAC in Lusikisiki can have consequences for the male participation in the organisation as well as the programme. For instance, the fact that TAC in Lusikisiki is dominated by women could have an effect on the mobilisation of men. In an area where patriarchal relations dominate, do women have the necessary authority to educate and mobilise the men?

One informant[71] considers TAC the most powerful and domineering organisation in Lusikisiki. The informant argues that the fact that the community believes in the help of TAC makes them powerful. The community invests power in TAC as long as they believe that TAC is a local institution where they are likely to receive assistance with their problems. The informant argues that the local women in particular see TAC as a powerful ally. And in many ways TAC Lusikisiki is dominated by women. The 3 permanent staff are all women as are the majority of the volunteers receiving stipends. And the people that come in searching for assistance are mainly women.[72]

TAC Lusikisiki has also established a gender desk that has assisted numerous local women with cases of rape and abuse. Women come to TAC to seek support and report their cases of abuse. TAC then uses its power and influence to get the cases reported to the police and follow-up the cases which end up in court.[73] One of the first tasks of the gender desk was to change the discourse from talking about 'victims of rape' to 'rape survivors'. Secondly, they established support groups for the 'rape survivors'.[74]

> Now, people are empowered. They can be able to talk about their 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.[75]

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[71] Interview academic informant 31.03.07
[72] My observations
[73] Interview TAC 2 24.03.07, interview TAC 1 24.03.07, my observations
[74] Interview TAC 4 13.03.07, interview TAC 2 24.03.07
[75] Interview TAC 2 24.03.07

In other words, the community mobilisation has not just led to changes in treatment literacy, but also to changes in awareness and responses in a case of rape:

> Here in Lusikisiki, there is a high rate of rape. But through the community mobilisation that we do, people now are able to understand that you can not 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.[76]

TAC at the national level has previously been criticised for having a male dominated leadership despite the organisation having a predominantly female membership base. Nevertheless, at the grassroots level the organisation has provided women with opportunities to lead the struggle against HIV/AIDS (Friedman and Mottiar 2004), as in the case of Lusikisiki. It can be argued that TAC in Lusikisiki has contributed to women's empowerment through their participation in the organisation and through establishing the gender desk assisting vulnerable and abused women. However, persisting patriarchal relations coupled with local dominance of women in the organisation and programme could be preventing the men from getting engaged.

The TAC hierarchy

TAC in Lusikisiki is a district office that is supposed to cover the whole of OR Tambo District with its population of about 1,8 million people, but in reality focuses on the Qaukeni municipality of which Lusikisiki is a part.[77] According to all of my TAC informants, the large area that they are intended to cover presents substantial challenges to them. For instance they are being approached by hospitals in far-away corners of the districts that want to be accredited as ARVs sites and need TAC to do mobilisations for them. Unfortunately, they lack the capacity to cover such a large area. The result is that they do not get as much time to focus on Lusikisiki and the tasks around the programme as needed. It was however proposed by the national office that they should only focus on Lusikisiki in the future, to rather make sure they perform quality work in this particular (though still large) area and are thus able to more easily see the result of their work.[78]

[76] Interview TAC 2 24.03.07
[77] Interview TAC 1 24.03.07
[78] TAC national representative speaking at a HAACO seminar 04.03.07

The Lusikisiki office is subordinate to the Eastern Cape provincial office and there is a rather limited autonomy resting at the local level. Almost all planned TAC activities in Lusikisiki need to be approved on a higher level of TAC before they are implemented. Whenever they want to organise an activity, they will draw a plan and send it to the provincial office, which then approaches the national office for approval of the activity. Most inquires go from Lusikisiki via the provincial office, rather than directly to the national TAC.[79] The centralised decision-making presents challenges to the work in Lusikisiki as they waste time waiting for approvals from above.[80]

The decision-making independency in Lusikisiki can to a large extent be explained by a financial dependency on both external donors and the provincial and national levels of the organisation. The external actors funding of TACs activities in the programme will be discussed in the third chapter of the analysis. Also within the organisation, TAC strictly controls their finances on a national level. In order for a province to obtain funds, they need to submit monthly budgets for approval. Should additional funding be needed urgently, it is obtainable through submitting a detailed account of the activity (Friedman and Mottiar 2004).

For the Lusikisiki office, this implies that their monthly budgets need to be approved and incorporated at the provincial level and then later with the national office. It could present a problem for urgent activities on a local level when they have to go through extensive administration and approval in order to obtain funds. On one particular occasion during my stay in Lusikisiki, I could clearly see it presenting a problem for the organisation. They were trying to organise the public dialogue on the NSP, and numerous TAC activists were scheduled to come from all over the province. Hence TAC in Lusikisiki had to organise accommodation and food for a large number of people, which required funds they were not in possession of. So when an office higher up in the hierarchy took its time approving the application for funding, TAC in Lusikisiki was left completely powerless not knowing where else to obtain this sum of money. Hence, until the well overdue arrival of the money they were left more or less paralysed to do anything.[81] It illustrates how the tight control of money at top levels in TAC can kill or at a minimum temporarily paralyse activism at the grassroots level.

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[79] Interview TAC 1 24.03.07.
[80] Interview TAC 3 25.03.07
[81] My observations and informal talks with TAC Lusikisiki staff

Nevertheless, the cooperation and relation between the province and the district office is generally very good and supportive, according to the TAC informants. In the mobilisations around the NSP, TAC employees and volunteers came from the other offices in the province to assist Lusikisiki in both the planning and carrying out the mobilisation. There was even a representative from the national TAC office participating in the event. But in the presence of profiled and experienced TAC members from the provincial or national office, the local activists seemed to somehow withdraw and leave all action up to the 'outsiders'. This was unfortunate as there were several language barriers between those arriving from urban areas attending the mobilisations and the rural communities of Lusikisiki. The 'Xhosa'[82] spoken in urban areas of the province is different to that of Lusikisiki, as the former has been mixed with English and the latter is typical of the part of South Africa in which Lusikisiki belongs (also called Pondo-land). This problem was recognised by the representatives from higher levels of the organisation. It became a discussion at one of the community mobilisations, and the local activists were encouraged to speak up and lead the mobilisation.[83]

Also Friedman and Mottiar (2004) recognise a 'tension' between the leadership and the base of the organisation, which silences grassroots activists in their presence. They consider this to be a problem limited to TAC National meetings and that the activists remain active on the ground. Hence, they do not take into account the situations where representatives from the national or provincial offices appear at local events to support their comrades. It seems that to a certain extent the presence of people that are higher up in the TAC 'hierarchy' has a silencing effect on grassroots members also in Lusikisiki. On the one hand, it could simply be due to a respect for authorities. On the other hand, Friedman and Mottiar (2004) dedicate it to a question of levels of education and articulation separating the grassroots from the leadership. However, in a local context such as Lusikisiki, it is the local activists that have the best knowledge of the area and the people. It is thus unfortunate if leading the mobilisations becomes a question of levels of education and abilities of articulation. As argued above, being well-articulated has little effect unless the activist and the community speak the same language.

[82] Xhosa is one of the 11 official South African languages spoken by about 7.1 million people (National Virtual Translation Center 2007).
[83] My observations.

Yet, the fact that TAC in Lusikisiki is part of a larger national organisation can in many ways be considered one of the strengths of the organisation. Being part of a strong national organisation presents an opportunity for elevating local matters to a higher level of politics, as in the case of task shifting and adherence counsellors which will be discussed in the coming chapter. Belonging to an organisation operating at the national level thus increases their level of capacity. Simultaneously, the participation of representatives from higher levels of the organisation in the local events provides TAC in Lusikisiki with important resources and experience for their mobilisations.[84]

The case of TAC in Lusikisiki does illustrate that there is space for grassroots activists to climb the somewhat hierarchical ladder. The 3 staff members of TAC Lusikisiki all started as volunteers in the organisation shortly after is was established in the area and worked their way up to becoming employed as staff. Hence TAC in Lusikisiki is not an elite or professionally led office. Whilst the staff in the provincial and national office may be professionals rather than former volunteers,[85] the Lusikisiki staff came from the grassroots. They have a heavy workload and a lot of stress without earning large amounts of money and their work seems to be driven more by idealism and a genuine wish to help people in difficult situations rather than professional motives for their job. As one informant puts it: "We are benefiting because we are saving people's lives."[86]

The Lusikisiki-based TAC district office has 22 branches, as many as 19 are located in the Lusikisiki communities, where each of the areas' 12 clinics has a branch located nearby. The branches are an important source of information from the district office as they report to the office regularly with news from their respective communities. It means that the organisation is always up to date about what happens in the various communities around Lusikisiki, for instance about rapes or other cases of abuse.[87]

TAC in Lusikisiki is aiming to empower the branches to work independently, both to relieve the district office of some of its workload, but also to build and ensure the sustaining of grassroots participation and activism in the various communities. However, they are dependent upon the district office for financial support and thus need the approval of the

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[84] My observations.
[85] Interview TAC 3 25.03.07
[86] Interview TAC 3 25.03.07
[87] Interview TAC 3 25.03.07, interview TAC 1 24.03.07, interview TAC 4 13.03.07

district (which gets the approval higher up in the hierarchy) to implement their plans and activities. The lack of financial means is furthermore a problem for the branches that are run by volunteers who do not get paid for their work. The branch-volunteers ask for the stipends because it is not possible to do the large amounts of work without the money, particularly not when you have a family to feed.[88]

> There was a loophole with the branches, because these people were working voluntary since 2003 some of them, and they are getting nothing...by the end of the day they become fed up…They are still needed to be working as volunteers, but you know, there are expectations…if you are a human being. So they are expecting that 'if I am doing this, maybe I can get…'. But what I like about TAC; we didn't hide anything…We just put it to the table that if you are going to be a volunteer to TAC you are not going to be paid anything...So we just explain and people say 'ok, even then, even if it is so...we can do work voluntary...but they finish one year, they finish two years and 'this TAC is not coming with anything'. So they just leave…They don't stay long...If they stay long, sometimes they are just having a bad influence on the organisation. So that they can just leave.[89]

The lack of money is also a challenge to the peer educators and TLPs receiving a stipend from TAC. They complained that the stipend was not sufficient income as the work they were doing was the equivalent of a full-time job.[90] Such lack of financial support thus presents a challenge to TAC if it means they are loosing people who possess valuable experience and knowledge both about their respective communities and the organisation. It can thus be argued that the human resources available to TAC need to be catered for as they are an important part of the structure and work that TAC is doing in the communities. Nevertheless, in most cases there seems to be good cooperation and communication between the district office and the branches who attend monthly meetings where the branches submit their reports and identify their challenges.[91]

Other challenges to the mobilisation

Unfortunately, TACs involvement in terms of for instance advocacy work in the clinics has resulted in negative attitudes towards the organisation amongst some of the health personnel. Clinic personnel seemed very weary of their presence and reluctant to assist in fear of what the consequences might be for their job or the clinic. There are clinics in Lusikisiki that TAC

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[88] Interview TAC 1 24.03.07. The stipend is a monthly payment provided to some of TAC volunteers performing specific tasks, such as peer educators.
[89] Interview TAC 3 25.03.07
[90] Interview TAC 5 13.03.07
[91] Interview TAC1 24.03.07, interview TAC 4 13.03.07

have problems approaching, because the clinics are afraid that if they give TAC free entry to their clinics and access to information, they will see them 'toyitoying'[92] against them a few days later. This does create a number of problems for TAC when they wish to acquire information, statistics or simply do appointments for an upcoming community mobilisation.[93]

Nevertheless, TAC has also campaigned around the nurses challenges in Lusikisiki and for improvements of their living conditions. Simultaneously they have lobbied for new clinics to be built in underserved areas (MSF 2005). Hence, it can be argued that TAC and the health care workers relations are variously characterised by opposition as well as engagement. A discussion on TACs employment of both politics of opposition and politics of engagement in Lusikisiki follows below.

The TAC politics of mobilisation

"The experience of social mobilisation in the anti-apartheid struggle continues to inform the tactics and strategies of civil society activists today" (Camay and Gordon 2004:42). And TAC is one example of a civil society organisation which has successfully employed strategies from the struggle against apartheid (Strand et al. 2005). However it can be argued that TAC mixes politics and mobilisation. On the one hand, they are mobilising for treatment literacy, community participation and enrolment in the programme. On the other hand, there is an ongoing mobilisation for the right and access to universal ARVs and participation in policy-making. According to the TAC treasurer: "In making these claims on government, TAC continues a tradition of human rights advocacy that the ANC itself pioneered" (Heywood 2005:23).

The dual face of TAC

As discussed above, TAC has played a crucial role in Lusikisiki through their social mobilisation of the community which has educated people about HIV/AIDS and treatment and made people come to the clinics to get tested and enrolled on the programme. It can be argued that this role is largely linked to that of a service-delivery NGO illustrating their

[92] 'Toyitoying' is a word used in South Africa for activism similar to 'demonstration' and 'protest' (according to my TAC informants), which has close links to the anti-apartheid movement (Marinovich and Silva 2000). I have chosen to employ the use of the word in its original form as this is the word used by my all my informants and a word that they relate to.

[93] Interview TAC 3 25.03.07, interview TAC 1 24.03.07, my observations

involvement in the 'politics of engagement', as outlined in the theoretical framework. On the other hand, they have taken an activist or rights-based approach to the social mobilisation thus employed what Habib and Kotzé (2003) labelled 'politics of opposition'. The balancing of these two roles, between being a service-delivery NGO and a social movement, has to a large extent been acknowledged as a key to TACs success, but at the same time caused confusion and troubled relations with the state.

> In Eastern Cape, how it has worked for TAC to be quite recognised 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.[94]

The way that TAC is able to balance and shifts roles depending on the context is in many ways characteristic of their work. They have goals that they want to achieve for PLWHA in South Africa and often assist government in reaching those goals acting as a service-delivery NGO. However, when government blocks or slows down progress in reaching those goals, TAC pulls out their activist side and takes on the role of a social movement in their mobilisation. In other words, one day they are cooperating with government and the next day they are demonstrating against their lack of action.

The question is whether TACs balancing between the two roles is in fact a limiting and explanatory factor for the troubled relations between TAC and the DoH. To a certain extent it is a limiting factor and could explain the negative attitudes within government towards TAC. Still, it was something that TAC in Lusikisiki experienced frustrating, as they did not feel that their role in service delivery in the programme was recognised:

> I think the problem is they are still taking TAC as someone who are just toyitoying...They are not seeing that other side, doing treatment literacy that are helping people, they're just taking us 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.[95]

On the other hand, it could become difficult for government officials to deal with a civil society actor that wants to be a partner of the DoH the one day and seemingly opposing their

[94] Interview EC TAC 3 30.03.07
[95] Interview TAC 2 24.03.07

policies and action the coming day. The DoH can be argued to choose to withhold information if believing that the possession of this information will lead to 'toyitoying' by TAC.

However, according to the TAC treasurer:

> The TAC has adopted a political strategy that always preferred 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 2005:19).

It can also be argued that the balancing of the two roles is part of the organisation's capacity. The ability to make use of activism has added a pressure component on government to ensure service-delivery for PLWHA. Even staff at the hospital HIV-unit said that they work hand-in-hand with TAC and that the organisation was aware of their problems and ready to assist.[96] In other words, TAC seems to be considered as an important source of support by people working in a challenged environment in the health sector. The informant in the hospital indicated that it is by 'toyitoying' TAC is believed to have the greatest impact on ensuring service-delivery. Yet it is a somewhat paradox that it is this strategy of influence that in many ways is contributing to fragile relations with the DoH.

TAC has also struggled with having these two faces within a donor context. Most donors choose to only fund their public service-delivery side and condition their money from getting used for activist purposes. It is particularly the treatment literacy programme that is popular amongst the donors. In Eastern Cape, this programme together with the social mobilisation is being funded by UK Department for International Development (DFID), but the funding for any confrontational activities has to be coming from the TAC national office.[97] For TAC in Eastern Cape, this presents a problem as they see their two roles as being integrated and inseparable. To illustrate this, an informant[98] uses the example of TAC assisting in preparing a treatment roll-out in a hospital. To assist government in the roll-out, they will be doing patient mobilisation and treatment literacy. However, even though the community and

[96] Interview Adherence Counsellor 4 22.03.07
[97] Interview EC TAC 3 30.03.07
[98] Interview EC TAC 3 30.03.07

patients have been prepared, the government is moving frustratingly slowly with the roll-out. Consequently, TAC needs to pull-out their activist side in order to push the government to start the roll-out. In order for a roll-out to succeed, they need to use all forms of social mobilisation, not just focusing on treatment literacy which will render useless if there is no treatment available. The problem arises when donors refuse to recognise their activist side as sometimes being a necessary component of a successful treatment roll-out.

My academic informant[99] also expressed this view. He believes that the community mobilisation is the backbone of TAC and together with 'toyitoying' it is sometimes the only way to confront the government. His view is that the balance between their activist side and their public service-delivery side is one issue that TAC has well managed.

Still, when TAC in Lusikisiki feels that the government is not recognising their role and partnership, TAC becomes frustrated and see no alternative to voice their opinion but through activism. "Some say 'we don't like those illiterate persons'...cause we are always fighting, because we are not educated...It won't change, so we have to toyitoyi after that."[100] If the DoH does not include TAC in the decision-making processes, it could further fuel the use of 'toyitoying' to ensure the rights to participation. However, this mode of mobilisation and activism could then feed into the perceptions of TAC as anti-government, hence further jeopardizing collaboration between the two.

The 'old' versus the 'new struggle'

According to Migdal (2001), a social force or organisation's power to influence and change behaviour and beliefs partly depends on its capacity to generate symbols that people attach themselves to. And TAC has to a certain extent managed to generate such a symbol. They have employed means of mobilisation that has attracted people's attention and support for their cause of rights to health care.

The anti-apartheid movement made use of revolutionary songs in their mobilisations in the struggle against apartheid. Today these songs are still very much alive though used for quite a different struggle than that against apartheid. TAC has adopted the songs and is using them in their community mobilisations. The melody is the same, but some of the lyrics have been

[99] Interview academic informant 31.03.07
[100] Interview TAC 4 13.03.07

changed to fit with the context of HIV/AIDS (Robins 2004a).[101] Hence, the songs from the old struggle have been implemented in what has been labelled 'the new struggle'; that against HIV/AIDS and for the roll-out of ARVs. It can thus be argued that the use of originally anti-apartheid songs for post-apartheid purposes places TAC in a symbolic history of the country. These revolutionary songs seem to generate a genuine interest and curiosity in various communities. People would come out of their houses and turn up from the maize fields to find out what 'the fuzz' was about.[102]

One informant in the Eastern Cape TAC explained why they are using the old liberation songs in the context of HIV/AIDS:

> 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 country...That's why we feel that we are in a revolution when it comes to HIV/AIDS...So our songs...its 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 a struggle when it comes to HIV, up until...there is universal access to ARV treatment.[103]

However, the use of the anti-apartheid songs causes negative attitudes within the government, particularly the DoH, as these were songs that many government officials have close relations to and consider revolutionary songs.[104] It is not unlikely that it feels as if 'their own songs' are being used against them. It could add to the picture of TAC as anti-government and an organisation that might pose a potential threat to the government. These songs are no less powerful in the former Transkei, part of the homelands in the apartheid era, an ANC stronghold where many post-apartheid political leaders originate. Still, TAC national maintains that they are dominantly ANC supporters and only concerned with 'the politics of health' rather than 'politics *per se*' (Friedman and Mottiar 2004, Heywood 2005).

From my interviews, it appeared that most of the TAC Lusikisiki members had not reflected upon why they used these particular songs and the potential consequences of the usage. They recognised that the songs was a good way of attracting people in the rural areas when they did

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[101] Interview EC TAC 3 30.03.07, interview academic source 31.03.07, TAC 1 24.03.07
[102] My observations
[103] Interview EC TAC 1 19.03.07
[104] Interview EC TAC 3 30.03.07, academic informant 31.03.07

their mobilisations, but they seemed not to have reflected upon the consequences it might have on their relations to the state. In contrast, leaders on the provincial level seemed very much aware of the effect it had on relations to the state and politicians and that it appeared provocative.

Concluding remarks

The social mobilisation of the communities in Lusikisiki has to a large extent led people to seek testing and treatment at the clinics, educated people about their rights and created openness and knowledge about HIV/AIDS. TACs focus on treatment literacy appears to have increased the communities' knowledge of the available drugs as well as their rights to these drugs; hence the patients have started demanding these drugs from the clinics. However, there are a number of issues related to both the success of and means of mobilisation. The community mobilisation has focused on the poor and unemployed populations largely ignoring middle and upper class fractions of the community. Hence, they have to a certain extent deployed a class-based politics that could further deepen class-divides in the area. In this scenario, despite HIV/AIDS being an epidemic that crosses traditional class boundaries, the programme becomes something that certain parts of the Lusikisiki community can not relate to. Furthermore, the female dominance of the programme and mobilisation contributes to making TAC an organisation of and for women, which thus has consequences for male participation and acceptance of the programme. It can be debated to what extent the sense of belonging and unity that TAC represents appeal more to women than men. Simultaneously, the hierarchical structures of TAC have led to a certain dependency on the agenda and actions taken on a provincial and national level of the organisation, affecting the local agenda and activities that take place in Lusikisiki.

Nevertheless, TAC in Lusikisiki provides an interesting case of how governance can be challenged and influenced at a local scale through their rights-based social mobilisation. The public dialogue on the draft of the national strategic plan can be seen as way of trying to ensure participatory governance in Lusikisiki through promoting community participation in the policy-making process. The level of treatment literacy and high number of people enrolled in the programme today would probably not have been achieved at such a pace without their community mobilisation. TACs participation and role played in the Lusikisiki programme

supports the argument presented in the theoretical framework that where local government needs to deliver services, there is often a need to engage in partnerships with NGOs or other civil society actors that have the potential contribute to the development of a particular area.

The case of Lusikisiki is also illustrative of how TAC has gone from being dominantly a social movement (Friedman and Mottiar 2004, Heywood 2005) to taking up more the role of a service-delivery NGO now that the bulk of policy on treatment for HIV/AIDS is in place. However, TACs role in the programme has not solely been directed towards service-delivery in collaboration with the DoH. Their approach to mobilisation use of revolutionary songs from the anti-apartheid struggle in mobilising for peoples' right to access ARVs. It can thus be argued that they have also employed activist modes of mobilisation to impact on the governance of HIV/AIDS in Lusikisiki. Simultaneously, it can be argued that the means employed in their social mobilisation has impacted on their relations with local government. The use of the revolutionary songs originally intended for mobilisation against the old regime, have created perceptions of TAC as anti-government and created obstacles to their participation in the programme, such as accessing information.

The way that TAC combines roles of being a service-delivery NGO with being an activist social movement is illustrative of a CSO that has managed to transcend the divide and combined the politics of engagement with the politics of opposition. They are on the on hand assisting the DoH with service delivery whilst on the other hand challenging their (lack of) action through putting pressure on DoH to implement policies and ensure the rights to ARVs.

6. POLITICS OF TRANSITION: FROM NGO PILOT TO GOVERNMENT RUN PROGRAMME

In this chapter, I will be looking at some of the issues related to the transition from being an NGO-driven pilot to a government run programme. An underlying theme of this chapter is first and foremost the politics of MSF, but secondly the opportunities for civil society actors to impact on local governance of HIV/AIDS. Firstly, I will analyse the impacts of MSF involvement in Lusikisiki. This is followed by a discussion of the challenges related to their temporary involvement. The remaining part of the chapter is devoted to discussions on how the impact of their departure has or can been mitigated.

The theoretical framework emphasised that NGOs have a contested role in development. It was for instance argued that external NGOs have the potential to open up spaces for communication and civil society participation and that their engagement can contribute to the development of an area. On the other hand, their engagement can also create dependency. When such actors engage in development projects they are under pressure to show the product of their aid, hence every project should ideally be a showcase. I will argue that through implementing innovative and rather radical changes in the local health care structure, MSF has attempted to impact on policies regarding the governance of treatment as well as creating a dependency upon their presence in Lusikisiki. I also argue that MSF has opened up new opportunities for participation for civil society actors and to a certain extent been acting as a link between TAC and the DoH.

The MSF impact

Improved access to health care in the context of HIV/AIDS

Prior to the entry of MSF, Voluntary Counselling and Testing (VCT) was only available in the hospital in Lusikisiki. By the time of their departure, all 12 clinics were performing VCT and there had been a rapid increase in the number of tests performed. And whilst there was no access to ARVs prior to the introduction of the programme, by late 2006, all 12 clinics and the hospital were providing the treatment and about 2200 people were receiving it (MSF and DoH 2006). The decentralisation of the health care to the clinic level provided the community with multiple entry points and it was thus easier access to HIV/AIDS treatment and care. MSF also

trained the area's health professionals and community health workers, improving the knowledge about treatment and care in the context of HIV/AIDS. Furthermore, the task shifting ensured that ARVs could be initiated at the clinic level. MSF also came with a set of nurses and doctors, which were running a mobile team supporting the clinics (MSF 2005, MSF and DoH 2006). It was originally intended that the DoH would establish its own mobile team to sustain the structure of clinic support. However, this team has largely not been operative since the MSF departure.[105]

Opening up political space and opportunities for civil society actors

As mentioned in the theoretical framework, external agents such as NGOs have the potential to construct spaces or improve communication channels where the community, the government and other agents of development can discuss and develop action on community issues (Chopra and Ford 2005). What did MSF do to facilitate such spaces and opportunities for participation?

In a way, the entry of MSF provided a change in the political space and opportunities for civil society actors' participation. It was as a result of the cooperation with MSF that TAC established one of its first rural offices. If MSF had not initiated the programme and requested for TAC to be a partner also in Lusikisiki, it is unlikely that the office would have been established at that particular time. In many ways, the MSF partnership opened up new opportunities for influence and participation for TAC. Despite having been in conflict with national government over the past years over the people's rights to ARVs, a partnership with MSF provided them with a place in the treatment collaboration with the DoH in Lusikisiki. Looking at the history of conflict between the DoH and TAC, coupled with perceptions of TAC as a largely 'toyitoying' pressure group,[106] it is unlikely that they would have been included in such a partnership had it not been for MSF.

It can be discussed to what extent MSF contributed to a more TAC friendly environment in Lusikisiki. TAC was already a known organisation within the local DoH, as the national DoH had been in numerous disputes with them since their establishment in 1998. It is likely that MSF contributed to a more TAC friendly environment by bringing them forward as an

[105] Interview MSF 14.02.07

[106] Interview DoH Lusikisiki 2 25.03.07. 'Toyitoying' is as a word used in South Africa for activism/protest as explained in previous chapters.

important ally in the fight against HIV/AIDS. Simultaneously, the TAC partnership with MSF meant that TAC was given a voice in Lusikisiki. As long as MSF maintained TAC as a partner, the DoH would have to deal with the organisation if they wanted to continue the partnership with MSF. Hence, in many ways, the relationship between the DoH and TAC in Lusikisiki was shaped by MSFs presence. However, MSF was not a solely popular agent within the DoH, which will be discussed below. Hence being an MSF ally could close as well as open up space.

My informant at the provincial DoH did not express warm feelings for TAC. The informant claimed to recognise their importance in the programme, but considered them difficult to work with. "They mobilise the community to participate and to utilise the government programmes...But at times, they might just come here and toyitoyi and say 'we want this'. Then this time they are coming to pressurise you for a certain service".[107] This also shows the problems related to TAC having 'two faces' as discussed previously. It is challenging for the government to have an organisation that the one day wishes to be cooperative and included in the programme, but the next day appears in demonstrations against government policies and work.

Nevertheless, perceptions of TAC had changed for with some of the people in the local DoH. At first the informant had not realised that TAC came as a part and parcel of their new partnership with MSF:

> When MSF came here, we were not aware that they were also activists...We were only aware when we were working with them...These people are also TAC. Because that was new to us, at first we could not understand because...their approach was pressure. At first we could not understand why they are giving us pressure, because we felt that we should be working hand-in-hand. Not to be pressurised as the Department of Health, but to be advised...In the middle of the programme, we realised that their importance was needed. It was necessary for TAC to be there.[108]

However, the question remains as to whether MSF itself constituted such a space for participation, or if they have managed to facilitate sustainable spaces, independent of their presence? In a way, MSF seems to have acted more as the actual channel of communication or information between the DoH and the civil society actors, rather than having created open

[107] Interview EC DoH 20.03.07
[108] Interview DoH Lusikisiki 2 25.03.07

and safe spaces for discussion. According to my TAC informants it was MSF who provided TAC with the information they needed from the DoH. TAC did not have a direct link for receiving information from the department. The DoH might have had little choice but to cooperate with TAC as long as they were one of MSFs main partners in the area. Still, one informant in the local DoH feels the cooperation has actually improved after MSF left Lusikisiki. They now have to deal directly with one another.[109] Yet, the TAC informants expressed that they were having grave problems of cooperation with the DoH after MSF left. Even if the spaces existed with the presence of MSF, they may no longer be present. It could thus be argued that MSF may have acted as a channel of communication whilst operating in the area.

The entry of MSF also opened up space and opportunities for community involvement in public health care. One of the central components MSF introduced in the programme was community participation. Hence, they engaged TAC to mobilise the affected communities, inform them about HIV/AIDS and the programme, and educate them about their rights to health care. According to MSF, it has been characterised as a programme with a high level of community participation and community ownership (MSF and DoH 2006).[110] Nevertheless, if the programme was initiated and developed by 'outsiders', to what degree is it possible to generate feelings of community ownership?

The fact that the model was designed by an international organisation without contributions of the local community makes it a top-down project to begin with. MSF had learnt from and built the programme largely based on the Khayelitsha experiences, though it was changed to fit a rural context. It was MSF that took the initiative, designed the model and then later approached the communities as they were implementing it. Hence, there was community involvement in the implementation, but a lack of community participation in the decision-making process of the programme. It can be argued that MSF did attempt to involve the grassroots in the process through engaging TAC. But as mentioned in the previous chapter, the voice of TAC is not necessarily representative of the grassroots or the larger community in Lusikisiki. Still, MSF claims that they promoted a large extent of community participation in the programme. If based on criteria that community participation in a project is characterised by mobilising community organisations to distribute the education messages to their

[109] Interview DoH Lusikisiki 2 25.03.07
[110] Interview MSF 14.02.07

constituencies (Chopra and Ford 2005), it seems that there was community participation in Lusikisiki. However, to what extent there was a representative voice from the community involved in the programme can be debated.

MSF impact on state policies

As discussed in the theoretical framework, donors and NGOs are central actors in the politics of governance. And through advocating for and implementing the Lusikisiki model, MSF has attempted to impact on state policies in South Africa. "It is the NGO that was here that has made an influence on the state on policy, because of the talk about task shifting."[111] MSF aimed to impact on policies and regulations regarding health professionals' tasks. In Lusikisiki task shifting was introduced as a way of solving the lack of health care professionals in the area and MSF wished to make the structures of the pilot permanent (MSF 2006). The MSF informant argued that the Lusikisiki HIV/AIDS programme has increasingly opened up opportunities for impacting on state policies in a context of HIV/AIDS. They now have an invaluable experience and all partners are being invited to debates and meetings around the country, giving them an opportunity to state their opinions in various forums.[112] And according to my DoH informants, policies on task shifting are presently being discussed at the national level. They are learning from the Lusikisiki model and it is not unlikely that other areas in South Africa will benefit from implementing task shifting in the future.[113]

According to Jones (2004a), the historically embedded view of donors as 'experts' still prevails. In the case of MSF in Lusikisiki, they have to a certain extent presented themselves as 'experts' through implementing new forms and structures of HIV/AIDS care in the area. The fact that an external actor arrived and starting giving 'directives' for how HIV/AIDS care should be performed and how the DoH was to manage such a programme, seem to have triggered some negative attitudes within the DoH. Whilst my informants in the local DoH maintained that the entry of MSF had been crucial for the successful implementation of the programme,[114] other informants argued that there was on the contrary very negative attitudes with certain leading individuals in the department with regards to MSF. There seems to have

[111] Interview EC DoH 20.03.07
[112] Interview MSF 14.02.07
[113] Interview EC DoH 20.03.07, interview DoH Lusikisiki 2 25.03.07
[114] Interview DoH Lusikisiki 1 14.03.07, interview DoH Lusikisiki 2 25.03.07.

been both pro and against MSF supporters in the department, where the latter possibly saw them as a threat to their position, authority and legitimacy as a DoH.[115]

The issues within the anti-MSF camp in the DoH seem to lie first and foremost at a provincial level, but also with central individuals within the local DoH. The organisation was feared as it represented a potential threat to the local officials' positions (Beresford 2004). This supports the arguments made in the theoretical chapter that the aid relationship is vulnerable to conflict as differing interests and actors meet and there is thus a struggle over power and influence. In Lusikisiki it can be argued that there has been such a struggle over power and influence between MSF and the local DoH. Both actors came into the collaboration with their different agendas, and simultaneously there are unequal balances in resources and power. MSF had the financial and technical means to implement the programme, though DoH had the premises. However, the knowledge and resources that was at MSFs possession most likely appeared threatening to the authority and legitimacy of at least fractions within the local government.

The dual face of MSF

MSF is an organisation largely driven by professionals. On the one hand they are a non-governmental organisation involved in projects assisting local government with service-delivery, using their professional knowledge and capacity to improve the access to treatment in Lusikisiki. This implies that they are performing an expert service-delivery role and that they do not have a political agency. On the other hand, they have introduced a programme with components which they have argued ought to be made into policies at the national level. "Whereas in the past MSF had sought to be neutral and non-partisan in its interventions, the conditions in South Africa forced the organisation to take a more overtly political stand" (Robins 2004b:3). Due to their interest of changing health care policies at the national level it can be argued that their agency is also political, at least in the South African context. And according to the former head of MSF in Lusikisiki, Dr Reuter, "the model we are implementing – it's not just a medical model; it's a model for human rights and ARVs as a part of human rights" (Reuter quoted in IRIN Plus News 2004:17). MSF was driven by more than an interest in rolling out ARVs in Lusikisiki. They have also voiced up for treatment for HIV/AIDS as a human right and for changing health care policies to succeed in realising these rights.

[115] Interview Adherence Counsellor 1 05.03.07, interview MSF 14.02.07

Hence, with the departure of MSF, it is not solely the professional agent and their aid that has disappeared. After their departure, some of the political leverage that was used to maintain the structures of the original programme, such as task shifting and adherence counsellors, has also eased. After they formally handed over their programme to government, they no longer have the mandate to interfere.

Challenges to sustaining the pilot

The case of the adherence counsellors and task shifting

All my informants argued that the MSF model is a comprehensive model that was relatively well functioning at the time of their presence in Lusikisiki. MSF shifted the workloads of the clinic staff and added new positions to the clinic structure, such as adherence counsellors. "From its inception the programme was designed to be integrated into the health care system" (MSF 2006:3). MSF entered Lusikisiki with an exit strategy planning for three years (Beresford 2004), but they ended up staying for close to four years. But what are the implications when a NGO-driven pilot is intended to become a government-run programme?

Hakan Seckinelgin (2005:351) is amongst those who argue 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 HIV/AIDS context". The case of task shifting and adherence counsellors supports this argument. These were new and innovative programme components which MSF introduced, but they were not sustained. Many informants felt MSF left too soon and that the programme was not yet sustainable when managed by the DoH.

The type of task shifting that was central to the original model for Lusikisiki, with nurses initiating ARVs and counsellors performing the pricking, came to an end when MSF pulled out and the DoH took over, as confirmed by all the informants. Such task shifting was diverging from the norm of having doctors in hospitals initiating and managing ARVs. The nurses' positions and power thus went through major changes as a result of MSFs withdrawal. As the original task shifting of the programme has been reversed, nurses no longer have the authority to initiate ARVs nor can lay counsellors do the pricking of patients. However, there is a serious lack of doctors in the area, thus the waiting list to get started on ARVs is growing

longer and fewer patients are enrolled in the programme.[116] The burden on the already scarce number of doctors will increase unless more doctors are recruited or other aspects of their workload are shifted onto nurses. The latter alternative does not necessarily solve any problems. It might simply require a more substantial task shifting when the nurses' already heavy workload is added to.

As argued in the theoretical framework, there is a need for HIV/AIDS policies to be contextual already in the formulation process. The case of Lusikisiki supports this. In a context where there is a high number of PLWHA and a serious lack of health care workers, particularly doctors, bottlenecks will be created when only doctors are allowed to initiate treatment. When MSF was present and pursued task shifting in the clinics, there was no waiting list to be enrolled on ARVs (DispatchOnline 2007).

Another innovative component of the programme was the adherence counsellors, which were PLWHA in Lusikisiki who got employed and trained by MSF. Each clinic was assigned adherence counsellors, working to educate and prepare new patients for ARVs, and to ensure they adhere to their treatment. Their role in educating people about the available treatment is another factor that is likely to have contributed to treatment literacy in Lusikisiki. These counsellors were a new feature of HIV/AIDS programmes in the South African context. And a number of my informants highlighted their vital role in making the Lusikisiki programme work. Some informants went to the extent of claiming that the adherence counsellors are the actual backbone of this programme, and that there is no way they could have achieved such good results in terms of high enrolment and low lost to follow-up, had it not been for the adherence counsellors.[117] Still, the DoH was unable to cater for them as their occupation is not part of the 'organogram' (the existing clinic employment structure). Thus there is no space for the employment of the adherence counsellors in Lusikisiki and they are excluded from the public health system as anything but volunteers.[118]

The issue of task shifting was by some government officials perceived as a radical divergence from the accepted norms for rolling out treatment. Nevertheless, MSF got approval from the provincial DoH to implement a strategy of task shifting in their pilot programme for

[116] Interview DoH Lusikisiki 1 14.03.07
[117] Interview MSF 14.02.07, interview HAACO 1 07.03.07, interview HAACO 2 07.03.07
[118] Interview DoH Lusikisiki 1 14.03.07, interview HAACO 1 07.03.07, interview HAACO 2 07.03.07

Lusikisiki. Then in early 2006, the DoH came with instructions to the primary health care clinics insisting that initiating ARV treatment could only be performed by doctors. This led to a large drop in the enrolment of new patients in Lusikisiki over a six months period. Hence the decision preventing nurses from initiating ARV treatment was reversed by the DoH (MSF 2007d). Unfortunately, after MSFs departure and the hand-over of the programme to the DoH, the strategy of nurse-initiated ARVs has once again been abandoned as confirmed by all my informants. The clinic staff argued that nurses being prevented from initiating the treatment were one of the main challenges they were faced with in the clinics, as it created bottlenecks for enrolment having to refer patients to the hospital or other clinics which were scheduled for doctors' visits.

Despite the challenges presented in the transition from being an NGO pilot to a government run programme, it was from the beginning intended to be integrated into the local 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" (Reuter quoted in MSF 2006:3). This quote by the MSF project coordinator in Lusikisiki shows that MSF was well aware of the policy challenges related to the task shifting they implemented. But why do you design a programme intended to be integrated in the health care system, based on nurses initiating ARVs, when you are familiar with provincial and national policies on HIV/AIDS care stating that ARVs can only be initiated by doctors?

Many of my informants argued that the main bottleneck lies at the national policy level. However there is nothing in South African rules and regulations blocking nurse initiation and prescription of ARVs. The bottleneck is created when the policy framework is being interpreted differently depending on the government officials (MSF and NMF 2006). My MSF informant also argued that the question of nurses' initiation of treatment was largely dependent on individuals or the level of government they operated on. "It depends on with who you talk...Province yes. If you talk to the district, it depends on the day. If you talk to national, it depends on who you talk with."[119]

Having discussed politics of scale and the limited authority in decision-making facing the local DoH, it can be argued that the policy bottleneck lies at the national level. As long as the

[119] Interview MSF 14.02.07

national DoH does not provide clear directives stating that nurses' initiation of treatment is acceptable, it is unlikely that lower levels of government will approve of task shifting. One informant in the local DoH said that they are not familiar with the policies of the national DoH in the case of nurse initiation of ARVs. And as long as they do not have a directive from them opening up for such task shifting, they will not allow it in Lusikisiki.[120]

This is divergent from the original vision of MSF. According to Dr Hermann Reuter, "We are handing over a whole package to the department, with all necessary structures to ensure continuity in place" (Reuter quoted in DispatchOnline 2007:1). And previously it was said that "the partners are now confident that the programme is well established under the leaderships of the Qaukeni district and the provincial teams" (MSF 2006:3). However, due to the major structural changes that were made by DoH in the programme, it seems that MSF had not sufficiently negotiated the sustenance of task shifting and adherence counsellors with the DoH. Hence, in order to sustain the programme it can be argued that the original pilot should have been based on pillars unifiable with national policies. Based on the fundamental changes in the structure of the programme that came as result of MSFs departure, it seems like MSF has created a dependency on their presence in Lusikisiki. On the other hand it can be argued that pilots are meant to test new innovations. And as discussed previously, MSF was aiming to prove that a treatment roll-out could be successful in a rural area.

"The sustainability of this program depends on formal recognition of the changes to the services that were required in order to provide comprehensive HIV/AIDS care" (MSF 2005:12). If the adherence counsellors are to be formally recognised as a part of the programme, their case needs to be elevated to a higher political scale. As long as it remains a local matter, it is unlikely that the national DoH will proceed in changing their 'organogram'. The counsellors will need publicity on a national level and they might need someone to lobby for them at the national DoH. Provided that they remain a small Lusikisiki based organisation, they do not have the capacity to do so. Nevertheless, TAC could have the capacity to lobby for the counsellors at a national level. As they have lobbied for the prices and roll-out of ARVs, they could lobby for the inclusion of adherence counsellors as an integral part of an HIV/AIDS treatment programme. And informants in TAC opened up for engaging in the

[120] Interview DoH Lusikisiki 1 14.03.07

adherence counsellors' situation, but there are certain conditions attached to this, which will be elaborated on below.[121]

Beresford (2004) argues that in order to impact on the policy situation, MSF may have to engage itself with provincial and regional policy-makers rather than focusing on the local scale. Fortunately, there might be a change in progress already. The new National Strategic Plan of 2007-2011 predicts that ARVs will eventually be received from nurses at primary health care clinics rather than doctors at hospitals (MSF 2007d). And the issue of task shifting is presently being discussed at a national level.[122] However, there is a need for the national government to clarify policies so that local government officials, programme managers and clinic staff receive explicit guidance, rather than opening up for individual interpretation of the policy framework as is happening today (MSF 2007d).

Shaping local power relations

It can be argued that MSF changed power relations within the health care system through their implementation of task shifting. Nurses in Lusikisiki were given more power and authority than what they had in other parts of the country, through being initiators of ARVs and managing the clinic programmes. When the DoH took over the programme and put an end to task shifting, this power and authority was taken away and many nurses left the area and went to be employed elsewhere. They went from having a large extent of power, authority and respect during the presence of MSF, to being 'ordinary' nurses again after their departure. It was not tempting for many of them. They had received substantial training and experience and could thus easily find a 'better' job elsewhere, for instance within the private sector.[123]

Simultaneously, MSF contributed to changing local power relations between state and civil society actors. They advocated for a large extent of community participation in the programme and put TAC in charge of educating the community about their rights in public health care. TAC then attempted to empower local citizens to speak up and demand their rights, as discussed in the previous chapter. The politicisation of health rights was something new in Lusikisiki and most people appear to have been unaware of their constitutional rights. Yet the above-mentioned empowerment of the local citizens has put additional pressure on

[121] Interview TAC 1 24.03.07, interview EC TAC 1 19.03.07
[122] Interview DoH Lusikisiki 1 14.03.07, Interview EC DoH 20.03.07
[123] Interview nurse 1 14.03.07, interview MSF 14.02.07

government in health-related service-delivery and calls for participation in the governance process that was previously not an issue. Hence, MSFs entry has shifted more power over to the people in Lusikisiki.

MSF also argued that the implementation of the programme had provided previously unemployed people with both jobs and the opportunity to participate in activities that were important for their community. Locals got jobs as for instance adherence counsellors or community mobilisors.[124] In other words, they have contributed to empowerment of local citizens both through job creation and through participating in something meaningful. The latter was particularly important for HIV-positive people it was an opportunity to assist people in similar situations, emphasised by my TAC informants. The perceptions of PLWHA shifted from being considered a 'walking dead' to being a resource, through having experience and knowledge that could be used to help others.

As indicated earlier in the chapter, MSF has also changed power balances in the area, through bringing civil society actors into the collaboration with government. Hence, civil society actors have been given a voice in the governance of HIV/AIDS in the area. It is no longer solely the state that persist the power and influence over such governance. As TAC was not operating in Lusikisiki prior to the entry of MSF, it can not be measured how their power balance has been altered. However, it can be argued that they have been provided with a certain extent of power in the Lusikisiki context through the established opportunities and space for participation in the governance process. Furthermore, the MSF-initiated establishment of the HIV/AIDS Adherence Counsellors Organisation (HAACO) has given Lusikisiki another central civil society actor that participates and influences local governance of HIV/AIDS. This will be discussed below.

The loss of a partner, a doctor and a friend

Almost all my informants expressed the loss of an important professional, colleague and friend. From what I was told and experienced in Lusikisiki, the local MSF branch had been dominated by one individual. People did not seem to recognise the difference between the organisation and the man. Hermann was MSF. MSF was Hermann. When people in Lusikisiki (including the informants) talked about MSF, they would quite often just say "he" or

[124] Interview MSF 14.02.07

"Hermann". He seemed to have been their strength, their shoulder to lean on, their teacher, their doctor and their friend. Despite efforts to empower the local civil society actors through training and accessing financial support for their activities, the organisations expressed a great loss of support with his departure making their work in Lusikisiki a lot more challenging.

The adherence counsellors lost their former employer and mentor. TAC expressed to a large extent the loss of their main ally and mentor with the departure of MSF. Who would now assist, support and lobby for their acceptance and participation in the programme? My impression is that TAC in many ways felt the withdrawal of MSF more than any of the other partners and organisations in Lusikisiki. MSF had trained and supported them in various ways. TAC and MSF would hold events together. Even if MSF could not participate in TACs 'toyitoying', they would still encourage and support it. TACs access to and source of information, both with regards to HIV/AIDS facts and programme updates, came to a large extent from MSF. They also funded TAC Lusikisiki and their activities. The funding has continued after MSF left, but TAC has been notified that they need to search for new sources of funding as it is scheduled to end shortly.[125]

According to the informants in TAC and HAACO, Dr Reuter was not simply managing the programme for MSF in Lusikisiki. He was also personally seeing to the patients and would use MSFs transport to go to their homes if they were too ill to come to the clinics. One family member of a patient enrolled on the programme said that: "I know that if that (white) doctor was still here he would have come and taken her away, she would not be suffering" (DispatchOnline 2007:1). The dependency on one man to make the programme work was emphasised by many of the informants.

Mitigating the impacts of MSFs departure

It can be argued that MSF acted as the middle-man of the programme, ensuring cooperation between the CSOs and the state, as well as the clinics and the department. MSF would make the DoH reports and information available to TAC and by including them as a partner contributing to acceptance of the organisation in Lusikisiki. They would bring the issues of the clinics forward to the DoH, and assist in any problems they may have. They were a central

[125] Interview TAC 1 24.03.07, interview EC TAC 3 30.03.07

actor of the programme, both because they were ensuring the communication and cooperation between the various parties involved and because of the knowledge and experience they brought to the area. So how has the impacts of their departure been mitigated? How to fill the gaps created by their departure?

The establishment of HAACO

When it became clear that the DoH would not employ the adherence counsellors, which MSF considered to be more or less the backbone of the programme, they came up with an exit strategy of establishing an organisation for these counsellors. They felt the programme could collapse without the presence of these trained counsellors, so they tried to mitigate some of the impacts of their departure by establishing an organisation that could sustain their role. The new NGO, HIV/AIDS Adherence Counsellors Organisation (HAACO) was to attract external funds, employ the counsellors and thus sustain their role in the programme. Hence, they have employed 19 adherence counsellors spread out in all the clinics and the hospital. HAACO signed a memorandum of understanding with the EC DoH and became operative as an organisation from August 2006 (EC DoH 2006).[126] The memorandum states that the provincial DoH will work on finding a solution to make the adherence counsellors' role sustainable. Unfortunately, the document is not legally binding (EC DoH 2006) and my informant in the EC DoH was not enthusiastic about the opportunities for their employment in the DoH.[127] In summary, a central component of the programme was sustained, though only temporarily. HAACO is scheduled to cease as an organisation in 2010. Simultaneously, HAACO was at the time of my fieldwork 100% reliable on MSF for financial support, but the funding from MSF was intended to terminate shortly.[128]

It can be argued that HAACO has taken over some of the roles of MSF. First and foremost, they have employed the adherence counsellors, thus temporarily sustaining their role in the programme. Secondly, they do to a certain extent act as an advocate and lobby for the clinics within the DoH. They inform about and discuss the challenges of the clinics with the local DoH. In this way, they are assisting DoH with monitoring and evaluation, as they approach them regularly reporting from their visits in the clinics. Thirdly, as MSF used to do, HAACO

[126] Interview MSF 14.02.07, interview HAACO 1 07.03.07
[127] Interview EC DoH 20.03.07
[128] Interview HAACO 1 07.03.07

also provides DoH with its own statistics from the clinics. The DoH then compares it to its own statistics before it is published.[129]

Whilst the clinics used to turn to MSF whenever they were facing problems, they now often turn to HAACO or TAC to find resolutions, assist them and communicate the message to the department. This is not to say that the DoH does not communicate with the clinics or that they do not take an interest in solving their challenges. However, the DoH is faced with the responsibility of the whole of Qaukeni local service area, meaning they do not have the capacity to focus all their resources in Lusikisiki, but rather have to divide them over a large area. Even though the DoH officials claimed they visited the clinics regularly, the CSOs and the majority of clinic staff felt otherwise. The adherence counsellors at the hospital would use the head of HAACO to communicate with the DoH for them.[130]

Based on my observations and interviews, I would argue that HAACO is to a certain extent filling the gaps left by MSF. Locals often assume MSF and HAACO are the same organisation. This is probably not simply because people see HAACO taking over MSFs work, but rather that they are using the same office that MSF was formerly based in and that most HAACO employees used to be employed by MSF.[131] It appears that HAACO performs a crucial role in providing the links between the various institutions and partners of the programme. Perhaps most importantly, they are providing a closer link and doing much of the communication between the clinics and the DoH.

Civil society united?

Social movements and NGOs may draw on various formal and informal networks and partnerships to impact on governance, as indicated in the theoretical framework. This is to a large extent also the case in Lusikisiki, where TAC has strategically engaged itself with other CSOs. One of TACs main partners in Lusikisiki today is HAACO.

As mentioned previously, HAACO assists in some of these challenges through acting as a channel of communication between the clinics and the DoH. But can they also act as a channel of communication between the DoH and TAC? Both the informants within TAC and

[129] Interview DoH Lusikisiki 1 14.03.07, interview HAACO 1 07.03.07, my observations.
[130] Interview Adherence Counsellor 4 22.03.07
[131] Interview HAACO 1 07.03.07, interview Adherence Counsellor 3 14.03.07

within HAACO seemed to value their cooperation as an important source of support in everyday activities and tasks. Most of the HAACO counsellors are TAC members, hence the patients are often referred to TAC for assistance or support.

HAACO provides an important source of information for TAC, as they are working closely with the DoH, thus receiving information about statistics and updates in the programme. Despite the unwillingness in the DoH to share information with TAC, HAACO 'secretly' shares the information it has been provided with. They would thus provide TAC with information about the programme that the DoH was reluctant to disclose. Simultaneously, TAC is regularly informed about HAACOs challenges and is offering to assist the counsellors in their fight for formalising their role in the programme. One of the counsellors felt the only way this could be achieved was for TAC and the counsellors to 'toyitoyi' together.[132]

However, HAACO has taken a different approach to the collaboration than that of TAC. It can be argued that it is their choice of approach which creates barriers for the unity and cooperation between the two CSOs. HAACO is also engaged in advocacy work, but they have taken less of an activist approach than that of TAC.

> On the one side, we need to advocate for the patients, on the other hand we need to be neutral, not to talk sides, for instance in terms of DoH and the community. But in terms of advocating for the patients, that is one of our main tasks. 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 premises...[133]

It can be argued that also HAACO has employed both politics of engagement and politics of opposition. Still, they are more oriented towards engagement and dialogue with the DoH, to advocate for the patients and clinic staff through engagement. They way that they prefer engagement over opposition generates more cooperative relations with the DoH than what is the case of DoH and TAC. HAACO argues that it is through engagement, and more specifically advocacy through engagement, that they have an impact on the programme and policy. Through only employing opposition in a context of engagement, the HAACO informants argued that they have a voice in the programme. Rather than engaging in 'toyitoying', they resort to direct communication with the DoH. "Like if it has to do with TB

[132] Interview Adherence Counsellor 4 22.03.07
[133] Interview HAACO 1 07.03.07

treatment, I go straight to the TB manager".[134] This is contrary to the case of TAC, where it seems to be their politics of opposition that is creating barriers to the politics of engagement with the DoH. It can be argued that due to their employment of means such as 'toyitoying' and opposition, they are not welcomed when they attempt to approach the DoH on collaborative terms.[135]

The two CSOs have thus taken very different approaches to the collaboration. And largely due to HAACOs focus on collaboration rather than opposition, HAACO has not been able to provide the kind of support and partnership that MSF constituted for TAC. It can be argued that they have to a certain extent taken the role of communication between TAC and DoH, because HAACO provides TAC with vital information about the programme which they have received from the department. However, most TAC informants both in Lusikisiki and the province called for the CSOs to unite in the politics of opposition, as they argued it is now only TAC who is putting pressure upon government to fulfil their responsibility. The TAC informants were a bit disappointed with the cooperation with HAACO, as the latter have refrained from supporting the TAC demonstrations and activism.

> HAACO now...is working as if it was on the party of the Department of Health. Because they don't want to loose this opportunity of working with the Department of Health. So they're just doing like this. But we as TAC, we understand that. We don't have a problem with that.[136]

HAACO does not wish to address or lobby for TAC interests within the DoH. They seemed to be largely refraining from being a partner of TAC in the public sphere, as it could cause the wrong perceptions of their organisation. Due to the existence of a somewhat divided camp in the Lusikisiki DoH between those actors who are pro- and those who are anti-TAC, partnering with and publicly supporting TAC can be perceived as pro-TAC and thus anti-government. HAACOs aim is to eventually be employed by the department. Hence, the leadership within the organisation restricts the participation of the employees when it comes to public events and support of TAC. The employees are not allowed to participate in such activities under the umbrella of HAACO. They feel that any 'toyitoying' would jeopardize not just their everyday

[134] Interview HAACO 1 07.03.07
[135] Interview HAACO 1 07.03.07
[136] Interview TAC 3 25.03.07

work and relations to the other partners, but more importantly their prospects of being employed by the DoH.[137]

The fact that TAC is the only organisation pressurising local government in Lusikisiki was a worry to many of the informants. "We don't want to be seen as a face of marches...We have to be able to sit in the meetings and to discuss some things".[138] The staff of TAC in Lusikisiki were aware of the impact their 'toyitoying' had on relations with the local government and called for other civil society organisations to join their forces with TAC. If the CSOs could unite in their struggle it could improve their relations with government, as TAC would then not be perceived as a single difficult civil society actor fighting government.[139] Informants both within TAC in Lusikisiki as well as in the Eastern Cape opened up for assisting HAACO's adherence counsellors to achieve their aim of becoming employed by the DoH. Still, they will not be the ones to take the initiative. It was argued that 'toyitoying' for HAACO would reinforce the image of TAC as a face of marches. Hence, they called for HAACO to take the lead.[140]

HAST – a space for communication and cooperation?

Even if the entry of MSF opened up spaces for participation for civil society actors, their departure has also led to changes in these spaces and opportunities. At present, the spaces for communication and participation can be considered a shortcoming of the programme. TAC is being blocked from accessing information from the DoH, illustrative of the lack of communication and cooperation between the two. However, MSF did establish an AIDS task team that aimed to involve all stakeholders in the programme from community representatives to DoH managers, traditional leaders to NGOs. This body is intended to coordinate activities and improve the implementation of the HIV/AIDS programme (MSF 2003). And the committee for HIV/AIDS, STI and TB (HAST) seem to be the only operative local mechanism for participatory governance in the context of HIV/AIDS in Lusikisiki. According to some of my informants, it is through HAST that civil society has been given a stronger voice than they did before the introduction of the HIV/AIDS programme. They are here given an opportunity to voice their opinion in a forum including the local government.[141]

[137] Interview HAACO 1 07.03.07
[138] Interview TAC 1 24.03.07
[139] Interview TAC 1 24.03.07, interview TAC 2 24.03.07
[140] Interview EC TAC 1 19.03.07, interview TAC 1 24.03.07
[141] Interview HAACO 1 07.03.07, interview Adherence Counsellor 1 05.03.07

It can thus be argued that the HAST meeting is a potential arena for solving issues of communication and nursing good state-CSO relations. It is intended to be a monthly meeting where the CSOs involved in the programme meet with government, discuss challenges and the way forward. The DoH officials were putting a lot of emphasis on the importance of HAST in the interviews and seemed to believe that the fact that there is such a thing as HAST should indicate that there are good state-civil society relations in Lusikisiki.[142] Nevertheless, HAST appears to have more of a symbolic meaning. It is a body that the government can always refer to when illustrating how they are making an effort in integrating the various CSOs and stakeholders in the programme. In reality, HAST meetings did not always take place. During my presence in Lusikisiki it occurred several times that the various stakeholders would turn up at the scheduled meetings only to be informed that no one from the department was present, hence they had to cancel the meeting.[143] There was no notice being given in advance.

As discussed in the theoretical framework, participatory governance on a local scale can lead to an opening up of space and of opportunities for civil society actors and a tool to keep government accountable to public service delivery. However, policies and initiatives taken to promote participation, does not in itself guarantee participation in the governance process. Whilst as HAST is recognised as an important participatory mechanism by the local DoH and a space where the various actors involved in the programme can come to discuss their challenges, it can hardly have such a function unless the meetings actually take place. On the contrary, the civil society actors that I interviewed were relatively frustrated by the lack of initiative and interest in HAST shown by the department.[144] This is in line with the argument that the extent to which policies on participation in governance actually opens up opportunities for civil society actors is largely dependent upon the local context. Unless the outcome of the HAST meetings lead to any actual changes in the programme, this intended participatory mechanism will have more of a symbolic than actual function. Still, if the meetings take place it does at minimum present opportunities for civil society actors to be heard in the process.

[142] Interview DoH Lusikisiki 1 14.03.07, interview DoH Lusikisiki 2 25.03.07
[143] Interview HAACO 1 07.03.07, interview TAC 1 24.03.07
[144] Interview HAACO 1 07.03.07, informal talks with TAC members and staff

Even if the assumptions are that hierarchical modes of governance have been replaced by horizontal modes such as partnerships and networks, as indicated in the theoretical framework, the case of Lusikisiki illustrates that this may simply be an assumption. In a way, horizontal modes of governance have been implemented through public-private partnerships in the programme and organisations such as TAC and HAACO are recognised by government as playing important roles. However, even if the roles played by the organisations are considered important by the government, how much influence does the civil society actors really have when the DoH remains largely inattentive to their challenges and demands? This indicates that the programme in Lusikisiki is still largely driven by hierarchical modes of governance. The NGOs perform their role in assisting government with service delivery, in line with the neo-liberal ideal, but when it comes to the policy level, their influence remains minimal. The DoH then appears to be the only decision-making body in the local governance of HIV/AIDS. However, as discussed previously in the analysis, the local DoH has limited authority in changing policies and is only responsible for the implementation of such. Hence, if civil society actors are to have an impact on policy, they might have to focus their attention on provincial and national government. Still, the local DoH has an opportunity to negotiate for civil society demands with higher levels of government. The local DoH informants argued that they do forward reports discussing policy-challenges, but it remains to be seen to what extent this can impact on policy-making.

Other participatory mechanisms - The AIDS council

One participatory governance mechanism that has been introduced in South Africa in the context of HIV/AIDS is the South African National AIDS Council (SANAC). The AIDS council is intended to be a multisectoral advisory body for the Cabinet. It represents both state and civil society actors and is engaged in reviewing and monitoring programmes and strategies, providing advice for government on HIV/AIDS, and to develop or strengthen existing partnerships in this context (South African Government 2007).

The Eastern Cape AIDS council is a body under the national council which is supposed to advice provincial government on policy related to HIV/AIDS, bring together stakeholders, monitor, evaluate and coordinate various actors' activities. They have representatives from different government departments and various civil society actors, including TAC. The local

AIDS council is a body under the provincial council intended to have the same functions though on a local scale. [145]

The building and development of the local AIDS council in Qaukeni (the local service area to which Lusikisiki belongs) is still in progress. Even though the council is intended to be a participatory governance mechanism in the context of HIV/AIDS, a space where the various actors involved are to be heard and have an opportunity to impact on policy-making and implementation, the council was not functional at the time of my fieldwork. However, there were people with the provincial AIDS council involved in developing and strengthening the council to realise its potential.[146]

Rather than this local AIDS council being an advisory body for the government, it is the government which acts an advisory body to the council at the moment. According to my informants in the local DoH, it is practically the DoH which runs the council and provides the directives for its work.

> They need to lead, they need to say: 'Now it is time for condom week. What has the department done about condom week?' That is their role, they have to lead the way. But here in Lusikisiki, it is the other way around. It seems to be the Department of Health who is always leading...We need to strengthen the council...In my opinion, they don't know exactly what to do...Here it is the Department of Health that is leading.[147]

In other words, if the local AIDS council is not a functioning body, this participatory mechanism remains an illusion in Lusikisiki. Another problem with the local council is that the bulk of its funding comes from the government.[148] This poses some questions regarding its independency and autonomy. If government funds the council, it could make it less critical to directives and requests coming from the government, thus biasing the council in the favour of the views of government rather than those coming from civil society or other stakeholders. And TAC informants argued that the local AIDS council were not supportive of the CSOs and that its members seemed to be uninformed of the tasks they were intended to carry out. TAC in Lusikisiki called for an empowered and functional local AIDS council with clear directives regarding its mandate. It could then act as a body assisting in solving the challenges of

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[145] Interview EC AIDS Council 21.03.07
[146] Interview EC AIDS Council 21.03.07
[147] Interview DoH Lusikisiki 2 25.03.07
[148] Interview EC AIDS Council 21.03.07

cooperation between the partners of the programme, particularly between TAC and the DoH.[149]

From pilot to programme

After 3 years involvement in Lusikisiki, MSF discussed a withdrawal with the DoH, but agreed that their presence was still required in the programme and stayed for another year.[150] However, the programme was always intended to be a temporary involvement for MSF, hence they left Lusikisiki in late 2006 (MSF and DoH 2006).

In summary, some of the consequences of MSFs departure have been dealt with. First and foremost, the local DoH has been trained and empowered to manage the programme. Secondly, MSF is presently involved in a follow-up of the programme.[151] Thirdly, they have attempted to sustain civil society involvement in the programme through continued financial support of TAC and HAACO. However, at the time of my fieldwork, both the organisations had been notified that the financial support was about to terminate, hence they needed to search for new donors. Fourthly, HAACO fills some of the gaps created by the MSF departure from Lusikisiki. Even if HAACO is not intended to replace all the roles played by MSF in relation to the programme, the establishment of this organisation has at least mitigated some of the impacts of their departure. MSF also has a member in the HAACO board, thus still having an impact on their activities in Lusikisiki. Even though MSF as an organisation is no longer physically present in Lusikisiki, I would say their influence over the two organisations is still high. Members of both the organisations looked upon MSF as their mother and father, and a continuing source of support.[152]

It should be taken into account that a pilot is always unique. A pilot is likely to have available a lot more resources, financially and technically, than a long-term programme. For instance, MSFs financial means meant that they were more flexible than the DoH and when necessary they would provide the extra time and resources needed.[153] And furthermore, “what is different is that we had the independence to do what we know is right, without waiting for government policy changes every time” (Reuter quoted in MSF and NMF 2006:12). Hence,

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[149] Interview TAC 1 24.03.07, interview TAC 3 25.03.07
[150] Interview DoH Lusikisiki 2 25.03.07
[151] Interview MSF 14.02.07
[152] Interview Adherence Counsellor 1 05.03.07, interview TAC 1 24.03.07, interview HAACO 2 07.03.07
[153] Interview TAC 1 24.03.07

sustaining a pilot will always be challenging and there is bound to be changes made in the transition from an NGO-driven pilot to a government run programme. However, there is a conflict between MSF and the DoH over policies and what action should be taken. For MSF, the results of the pilot were important for visualising the opportunity to succeed in rolling out treatment in an under-resourced rural area. On the other hand, they wish to see the sustenance of the model they implemented. For the local DoH, such sustenance is challenging the existing policy-context and they need to act in accordance with current policy directives.

Yet several informants argued that the programme had changed relations between the state and civil society in Lusikisiki, as the state was now providing its citizens with treatment. One informant argued that "now they know that our government that we voted for is giving us the treatment. Our families who are sick may live longer now that government has given this treatment."[154] In other words, it can be argued that taking over responsibility of the programme and the provision of ARVs also gave local government increasing legitimacy in relation to the community it serves. The citizens are now seeing that the government they voted for is finally managing the programme and providing them with life-saving drugs.

Concluding remarks

The case of the Lusikisiki HIV/AIDS programme illustrates the argument made in the theoretical chapter about how there are numerous actors involved in governance, and that the politics of governance take place on various geographical scales. Different geographical levels of government together with civil society actors and an external actor have been involved and struggled for influence over the programme and related policy.

The involvement of and partnership with an external (international) actor with its funds, knowledge and experience has to a large extent changed local health care structures and governance of HIV/AIDS in Lusikisiki. The entry of MSF in Lusikisiki opened up space and opportunities for civil society involvement, both for the community and for civil society actors such as TAC. Hence it can be argued that the degree of participation in local governance of HIV/AIDS has increased. However, their entry as well as their departure changed local power relations. Their entry led to increased power and influence for civil

[154] Interview Adherence Counsellor 1 05.03.07

society actors, when they were included as partners in the programme. Simultaneously, nurses in the clinics gained more powerful positions as they were trained in prescribing and managing ARVs and clinic programmes. Yet, this structure was once again altered when MSF departed and they were deprived of this authority.

MSF can be said to have a two-sided agency, as they on the one hand are occupied with service-delivery, but on the other hand were advocating for a change in national policy regarding task shifting and adherence counsellors. It can be argued that MSF had created a relative dependency upon their presence, as not all components in the programme were properly catered for after their departure. In 2004 it was argued that “the major problem is that the ARV treatment roll-out in Lusikisiki is dependent on MSF for expertise and resources” (Beresford 2004:280). Based on the discussion above I argue that this argument is still valid. Many informants felt MSF left too soon and that the programme was still dependent on their professional and financial support. Their strategy of task shifting has not been sustained, thus creating bottlenecks of enrolment in the programme. Simultaneously, the adherence counsellors have not been employed by the DoH. With the departure of MSF, some of the political leverage for changing policies has disappeared.

It can be debated to what extent it was right of MSF to build a programme based on components that were not sustainable due to policy bottlenecks. Despite their desire to see the creation of such policies in South Africa, they knew that the programme as they implemented it was not necessarily sustainable in the long-run. Also Beresford (2004) argues that it would be unethical to abandon the programme if DoH is not taking the necessary action to successfully run the programme. Yet, MSF had an interest in proving that treatment roll-out was possible in a ‘deep’ rural context and it was thus feasible to design the model with these components. Unfortunately, the South African government is divided over these policies. The barriers to sustaining task shifting lies at a national rather than local or provincial level. Even if there is political will in Lusikisiki, the local DoH is constrained by their superiors in the provincial and national DoH, and is unlikely to implement policies on task shifting unless they receive explicit directives from the national level.

However, MSF was always intending to pull out and leave the programme with the DoH. And what was the alternative? If they had not initiated the HIV/AIDS programme in Lusikisiki, it is unlikely that ARVs would have been rolled out so efficiently and at such an early stage, as

the South African government had just recently committed to the rolling out of ARVs. Due to there being minimal knowledge and resources available for such a task in Lusikisiki, the implementation of a treatment programme would have been far-fetched in the near future had it not been for MSFs involvement. Despite the creation of bottlenecks to the enrolment and sustenance of the programme due to the departure of MSF, the local community, government and health workers have been left with substantial knowledge of HIV/AIDS, treatment and management. The programme has furthermore illustrated that decentralised health care based on task shifting is a feasible solution to achieving a treatment roll-out in rural areas short of professional health care workers. And a large number of PLWHA are currently receiving treatment in Lusikisiki. The enrolment has further increased since MSF departure and about 2700 people in Lusikisiki were receiving ARVs in March 2007.[155]

The case of Lusikisiki both supports and rejects the argument that international governance structures and approaches to HIV/AIDS are being imposed on local and national governments. MSF came to Lusikisiki with a model they had designed that was largely new in a South African context. It was not forcefully imposed on a South African government, however it can be argued that they had little choice but to accept an implementation if they wanted to experience a treatment roll-out in the near future. MSF may have introduced an innovative approach that was challenging national policies. Their impact has not yet resulted in major policy changes, although the issue of task shifting is presently being discussed at a national level of government.

[155] Interview DoH Lusikisiki 2 25.03.07

7. CONCLUSIONS

The objective of this thesis was to study the politics of governance of HIV/AIDS treatment at a local level in South Africa. The thesis started by outlining a history of South African politics regarding HIV/AIDS treatment, which lead me to the identification of a local case, the Lusikisiki HIV/AIDS programme. This local governance process was then analysed employing a theoretical framework concerned with the politics of governance. The thesis was founded on three research questions and the discussions in the three chapters of the analysis thus built the foundation for answering these. In the following chapter of the thesis I will revisit and provide answers to the research questions. Furthermore, I will present a discussion on the 'dual faces' of the actors involved in the local politics of governance, as well as how the case is interconnected with a broader context of HIV/AIDS governance in South Africa. In concluding this chapter, I present some reflections on the transferability of my findings.

Partners united?

What characterises the partnerships and collaboration in Lusikisiki? And what are the main challenges to the cooperation? The collaboration in Lusikisiki has been characterised by three very different actors: one international NGO, one South African organisation and one state department. They engaged in partnerships as they had a common objective of making the Lusikisiki HIV/AIDS programme work. Whilst the partnership between MSF has been characterised by a large extent of cooperation and support, the partnership between MSF and the DoH, and even more so between the DoH and TAC, has been conflictual. The challenges to cooperation can to a large extent be explained by the different nature of the partners. The partnerships and collaboration have been influenced both by their different agendas and the means they employ to achieve such. However, when looking into the relations and collaboration with the different partners in Lusikisiki, what I found intriguing was the role that the internal structures and individuals played in shaping the programme, relations and partnerships. Simultaneously, the local DoH is being constrained by their limited autonomy creating challenges to cooperation in Lusikisiki. This will be further elaborated on in a discussion of 'dual faces' and of 'politics of scale' below.

Politics of opposition and engagement

What was the role played by civil society actors and how did this affect the programme and collaboration? It has been argued that TAC has played a pivotal role in the programme through social mobilisation. They have educated people about their rights to health care, increased treatment literacy in the targeted communities and made people come forward to get tested and enrolled on the programme. Due to their closeness with and ability to access the communities they are a crucial partner for MSF and the DoH in rolling out treatment and ensuring the success of the programme. Still, their role has not solely been limited to service-delivery in the programme, but they have also played a role in the politics of governance. Through advocating for people's rights to treatment and putting pressure on the DoH to implement the policies of treatment they committed to, they also employed a political approach to their mobilisation. However, employing strategies and means from the anti-apartheid struggle in their mobilisation has created problems for the cooperation with the DoH. By employing what has been perceived as political strategies in ensuring treatment roll-out they are perceived as anti-government and blocked from accessing information, thus creating barriers for the cooperation as well as challenges to their participation in the local governance of HIV/AIDS.

Creation of bottlenecks

What are the implications of making the NGO-driven pilot into a government run programme? The transition that the Lusikisiki programme experienced from being managed by an international NGO to being integrated into public sector programmes for HIV/AIDS presented several challenges to the programme. As a pilot, the Lusikisiki programme had the expertise and substantial financial resources of an international organisation. As a state run programme, they were integrated into an already under-resourced health sector and governed by state policies regarding treatment rather than NGO innovation policies. First and foremost, this led to the abandonment of the strategies of task shifting that had enabled under-staffed primary health care clinics to roll out treatment. Whilst there is not necessarily anything in national policies preventing nurses from prescribing ARVs and counsellors from taking over some of the nurse's role, such policies are nevertheless interpreted differently by government officials and programme managers. In the case of Lusikisiki, the have decided to abandon

such practices, resulting in the creation of bottlenecks for the enrolment of new patients in the programme. Secondly, they experienced a loss of human resources as much of the staff MSF had employed in Lusikisiki either left the area together with the organisation or did not get employed by the DoH. Thirdly, the clinics and civil society actors experienced a loss of support. MSF had not just trained them, but assisted them in the everyday challenges they encountered in their work.

'Dual faces'

It can be argued that all 3 central actors in the Lusikisiki programme have been characterised by what I refer to as 'dual faces'. The DoH is on the one hand acting as a unified actor designing and implementing policies. On the other hand, they are a dual state as there are differing perceptions and interpretations of policies within the DoH leading to various government officials either opening up and engaging in partnerships with civil society actors or blocking such cooperation through making it difficult to access information and participate. Whilst some government officials seem to recognise the importance of civil society actors and a 'state in society', others seem to be under the perception that it is the state *versus* civil society in perceiving the civil society actor as a threat.

TAC has a 'dual face' as they are on the one hand acting as a service-delivery NGO engaging in collaboration with government to ensure service-delivery in the context of HIV/AIDS, whilst they are on the other hand acting as a social movement employing activism to put pressure upon government on implementing or speeding up service-delivery. They are thus engaged both in *politics of opposition* as well as *politics of engagement*.

It can simultaneously be argued that MSF has a dual face. In a similar way to TAC they are engaged in both politics of engagement and politics of opposition. On the one hand they are a professional NGO engaged in improving access to treatment for PLWHA, thus implying they have an apolitical agenda and feeding into the technical notion of NGOs as service-delivery providers. On the other hand they have a political agenda as they are putting pressure on the government to change policies opening up for task shifting and the inclusion of adherence counsellors in their 'organogram'. By initiating and implementing a programme based on radical changes in the primary health care structure as well as making public statements in the

media and reports arguing that the only way to ensure the sustenance of the programme and roll-out of treatment in under-resourced areas is to change policies at a national level, they are using political leverage to promote their agenda of improving access to treatment. Simultaneously, they are creating new space and opportunities for civil society actors such as TAC through involving them in the collaboration with government. Secondly, they have a dual face as they are one the one hand playing an enabling role in Lusikisiki entering the field as an international NGO with substantial financial means and expertise creating new opportunities for treatment roll-out and access. However, as an international aid organisation they are also creating challenges to the programme when intending to assist only within a limited time frame. It created a bottleneck for the programme as their innovations and design of the pilot model made the programme dependent on policy changes for sustenance. Simultaneously it created a bottleneck for the civil society organisations that were dependent on MSFs financial support to sustain their activities in the programme. Hence, they played both an enabling and a disabling role in Lusikisiki, through their entry and through their departure.

Politics of scale

As mentioned in the introduction chapter, the case of study, the Lusikisiki HIV/AIDS programme is to a large extent interconnected with a broader context of national governance of HIV/AIDS. Lusikisiki may be a small community; yet the programme is part of a broader context in which there are actors involved at different political scales. On the national level the case is part of a bigger question following a transition from focusing on the politics to the governance of treatment. This question is less concerned with the right to treatment and increasingly with the policies ensuring such rights. The case of task shifting and adherence counsellors in Lusikisiki has been largely elevated to the national level of government after proving that such strategies are a feasible way of succeeding in treatment roll-out in a ‘deep’ rural area. It has been argued that there is not necessarily anything in South African laws and regulations preventing nurses from initiating ARVs, however, the policy framework is being interpreted differently by government officials at different geographical levels. There is thus a lot of confusion regarding what is or what should be the policies of treatment roll-out, creating a bottleneck for rolling out treatment effectively at the local level when task shifting is abandoned. At a local, provincial and a national level the issue of treatment for HIV/AIDS

is politically contentious and a source of both cooperation and conflict between the state and civil society as well as within the state.

Even though South Africa have attempted a process of decentralisation of power and decision-making aimed at locating developmental initiatives and the implementation of such with local government, there are still barriers to achieving this. Local government officials have to work within a limited space, where policies and directions originate from higher levels of government. Local government thus still has minimal impact on the policies they are implementing and politics of scale are largely impacting on the programme.

The future of the Lusikisiki HIV/AIDS programme can be argued to be dependent upon how policies continue to be interpreted as well as on the directives coming from the national level regarding policies on task shifting and adherence counsellors. Unless national government clarifies policies on task shifting, such policies are unlikely to be implemented in Lusikisiki. In this scenario, it is likely that Lusikisiki will be experiencing increasing bottlenecks regarding first and foremost long waiting lists to be put on treatment, thus slowing down the enrolment of new patients on the programme in need of ARVs. Simultaneously, without the formal recognition of adherence counsellors as part of the clinic ‘organogram’, the programme could experience a higher degree of lost-to-follow up and problems of patients not adhering to treatment. However, the question of the adherence counsellors is also something that needs to be solved at a national level of government. The local government does not have the authority to change the clinic ‘organogram’, as they themselves expressed.

Both TAC and MSF are engaged in the politics of scale. MSF are on the one hand an international organisation, and on the other hand engage in policy debates at a national level in South Africa as well as service delivery on a local scale, illustrated through the case of Lusikisiki. In South Africa they have engaged in partnerships on all scales, with TAC at the national, provincial and local level, as well as the DoH on first and foremost a provincial and local level. They are also engaging in policy debates at the national level using a local case as reference to impact on higher levels of government. TAC also engages in partnerships and campaigns running from the top to the bottom of the geographical scale. On an international level they have allies such as MSF, on a national level they campaign and engage in partnerships for the rights to and roll-out of treatment. Simultaneously they have offices operating on the provincial and district level and below these they have local (grassroots)

embeddedness through their branches and through participating and assisting with local public service-delivery in the context of HIV/AIDS.

Lessons for the future?

As this thesis was based upon a qualitative case study approach in a specific context of a rural HIV/AIDS programme in South Africa, there is a need to discuss the transferability of the findings presented in the previous chapters. To what extent can this study contribute to an understanding of and preview of other situations?

This case study is of relevance within research on local governance of HIV/AIDS, as it is likely to be one of the first out of numerous rural HIV/AIDS programmes implemented in South Africa. Some programmes are already in the process of implementation and there are more to come because of the government's commitment to roll out ARVs across the country. The lessons that can be learned from looking at the collaboration and governance of this programme can be useful for designing and implementing other HIV/AIDS programmes particularly in a South African context of public-private partnerships.

As the programme was intended to test a model for rolling out treatment in a rural area, the lessons learned here could be valuable to take into account when rolling out other rural treatment programmes in South Africa as well as the Southern African region. Simultaneously, the results produced in Lusikisiki, first and foremost regarding task shifting and the employment of adherence counsellors, have shown that such a model for a treatment programme is feasible to implement and likely to produce good results in resource-constrained settings with a lack of professional health care workers.

However, the specific time and space this programme developed in needs to be acknowledged. The programme was designed and implemented at a time when the national policies on HIV/AIDS treatment had changed radically. The political climate had changed and space was opened up for the implementation of treatment programmes. This creates both spatial and time limitations for the transferability of my findings. Nevertheless, the governance process experienced in relation to the Lusikisiki programme can be illustrative of

what is happening or what could happen in other HIV/AIDS programmes in South Africa, as they are likely to be faced with many similar structural and political constraints.

In summary, this study can be useful to understand or preview other similar governance processes if taking account of time and space. Simultaneously, lessons learned from the Lusikisiki programme can be employed as tools for developing new models and programmes for rolling out treatment for HIV/AIDS in other rural areas.

Furthermore, this study of the Lusikisiki HIV/AIDS programme illustrates the need to study governance politically. The various actors involved engaging in collaboration and opposition illustrates that 'governance' is far from a simple technical notion. Governance is on the other hand largely concerned with politics, both through engagement and opposition, where numerous actors within the state and society struggle for influence and power over changing the agenda and structure of (local) governance.

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APPENDIX 1

Interviews

Below follows a list of all interviews conducted for this thesis, including those not referred to explicitly in the text. All the informants have been made anonymous and are thus referred to with codes such as 'Adherence Counsellor 1'. In order to protect the anonymity of the informants I have not listed the place where the interview was conducted.

Academic informant. An academic employed at a South African university. Interview conducted 31.03.07

Adherence Counsellor 1. Counsellor employed by HAACO working in a Lusikisiki clinic. Interview conducted 05.03.07

Adherence Counsellor 2. Counsellor employed by HAACO working in a Lusikisiki clinic. Interview conducted 09.03.07

Adherence Counsellor 3. Counsellor employed by HAACO working in a Lusikisiki clinic. Interview conducted 14.03.07

Adherence Counsellor 4. Counsellor employed by HAACO working in the hospital. Interview conducted 22.03.07

Doctor. A doctor employed by the Eastern Cape DoH working in a local hospital. Interview conducted 02.03.07

DoH Lusikisiki 1. A representative of the Lusikisiki Department of Health. Interview conducted 14.03.07

DoH Lusikisiki 2. A representative of the Lusikisiki Department of Health. Interview conducted 25.03.07

EC Aids Council. A representative of the Eastern Cape AIDS Council. Interview conducted 21.03.07

EC DoH. A director at the Eastern Cape Department of Health. Interview conducted 20.03.07

EC Socio-Economic Council. Representative of the Eastern Cape Socio-Economic Council, a body below the Eastern Cape government. Interview conducted 16.03.07

EC TAC 1. Staff at the Eastern Cape TAC. Interview conducted 19.03.07

EC TAC 2. Staff at the Eastern Cape TAC. Interview conducted 19.03.07

EC TAC 3. Staff at the Eastern Cape TAC. Interview conducted 30.03.07

HAACO 1. Staff at the HAACO office. Interview conducted 07.03.07

HAACO 2. Staff at the HAACO office. Interview conducted 07.03.07

MSF. A representative of Médecins Sans Frontières in South Africa. Interview conducted 14.02.07

Nurse 1. Nurse at a Lusikisiki clinic employed by the Lusikisiki DoH. Interview conducted 14.03.07

Nurse 2. Nurse at a Lusikisiki clinic employed by the Lusikisiki DoH. Interview conducted 22.03.07

Nurse. 3 Nurse at a Lusikisiki clinic employed by the Lusikisiki DoH. Interview conducted 25.03.07

TAC 1. TAC Lusikisiki staff member. Interview conducted 24.03.07

TAC 2. TAC Lusikisiki staff member. Interview conducted 24.03.07

TAC 3. TAC Lusikisiki staff member. Interview conducted 25.03.07

TAC 4. Active TAC Lusikisiki member. Interview conducted 13.03.07

TAC 5. Active TAC Lusikisiki member. Interview conducted 13.03.07

TAC 6. Active TAC Lusikisiki member. Interview conducted 23.03.07

APPENDIX 2

Themes for interviews

Social mobilisation
Modes and means of mobilisation
Treatment literacy
The importance of mobilisation for the programme
Impact on the community
Impact on local governance of HIV/AIDS
Changes in state-civil society relations

Task shifting
Nurse initiation of treatment
The role of adherence counsellors
Policy regarding task shifting

The organisation/work position
Tasks in the programme
Main challenges to their work
Solutions to work-related challenges
Inter-organisational relations
Degree of independency in decision-making
Community acceptance of the organisation's role
Main allies and main opponents
Opportunities to impact on policy-making and implementation (locally/provincially/nationally)
Mode and means used to impact
Gains from participating in the programme-collaboration

Collaboration and partnerships
Nature of partnerships and collaboration
Major advantages of cooperation
Major challenges/obstacles to cooperation
Solutions to these challenges
The different partners' impact on governance of HIV/AIDS
The programme's impact on governance of HIV/AIDS
Changes and challenges to MSF withdrawal

Future of the programme and collaboration
Prospects for sustaining the programme
Prospects for implementing the model elsewhere
Prospects for partnerships and collaboration