Civil society and democracy in post-apartheid South Africa: the Treatment Action Campaign, government and the politics of HIV/AIDS

by

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Abstract

Through an analysis of the case of the Treatment Action Campaign's (TAC) 'success' in pressuring the South African government to reform its controversial HIV/AIDS policy, this study will present a discussion of the concept 'civil society'. The confrontation between the TAC and the government has for the most part been framed within a neo-liberal perspective of state-civil society relations. This perspective tends to define civil society in terms of its structural properties in relation to the state: as a 'plurality' of associations, or organisations and social movements which possess the capacity to place demands upon the state; as the 'non-profit' or the 'non-government' sector, as a 'watchdog' of socio-economic or civil rights, as a 'counter-weight' to the power of the state, and so on. This study suggests that a neo-liberal perspective provides an inadequate understanding of civil society. It is argued that the term should be understood as a realm of activity in which citizens participate in the public affairs of the state. This understanding – referred to as a popular-democratic perspective – seeks to place an emphasis on the capacity of civil society to enable citizens to substantiate their lives as social and political beings. As a methodological device, the case of the TAC-government confrontation is selected as a means to demonstrate this theoretical argument. While the positive aspects of the TAC's 'success' are discussed, it is also possible to provide a more critical analysis from this perspective. Thus, in a 'post-TAC society', where the South African government has ostensibly committed itself to implementing an antiretroviral (ARV) rollout program, it is asked how citizens are to continue participating in the management and treatment of HIV/AIDS. To what extent, then, has the TAC enabled citizens to participate in the day-to-day issues surrounding the disease, and to what extent has it not?

Keywords: Civil society, democracy, citizenship, political participation, neo-liberalism, AIDS activism, the Treatment Action Campaign, South African government, politics of HIV/AIDS, Thabo Mbeki.

Abstrak

Hierdie studie poog om ‘n analiese van die konsep ‘siviele samelewing’ te bied deur om die Treatment Action Campaign (TAC) se ‘sukses’ om die Suid Afrikaanse regering se kontroversiële MIV/VIGS beleid te laat hervorm, te ontleed. Die konfrontasie tussen die TAC en die regering is oor die algemeen binne ‘n neo-liberale perspektief van staat-siviele samelewing verhoudings gesitueer. Laasgenoemde neig om die konep van siviele samelewing te defineër in terme van sy strukturele eienskappe met betrekking tot die staat: as ‘n ‘pluraliteit’ van verenigings of sosiale bewegings wat die kapasiteit besit om druk op die staat te plaas, as nie-winsgewende of die nie-regerings sektor, as die ‘waghond’ van sosio-ekonomiese of siviele regte, as teenvoeter vir die mag van die staat, ensovoorts. Hierdie studie suggereer dat ‘n neo-liberale perspektief nie die siviele samelewing voldoende kan beskryf of defineer nie nie en dat die konsep begryp behoort te word as ‘n terrein van aktiwiteit waar burgers deelneem in die publieke aangeleenthede van die staat. Hierdie popular-demokratiese perspektief op die konsep lê klem op die kapasiteit van die siviele samelewing om burgers aan te spoor om hulle lewens te substansieer as sosiale en politieke wesens. ‘n Ontleding van die TAC-regering konfrontasie word met ander woorde gebruik om laasgenoemde teoretiese argument te demonstreer. Terwyl die positiewe aspekte van die TAC se ‘sukses’ gëillustreer word, is dit terselfdetyd moontlik om ‘n meer kritiese analise vanuit laasgenoemde perspektief te lewer. Dus, in ‘n ‘post TAC samelewing’, waar die Suid Afrikaanse regering hulleself skynbaar daartoe verbind het om ‘n antiretrovirale (ARV) program te implementeer, word daar gevra hoe burgers vandag nog kan deelneem in die bestuur en behandeling van MIV/VIGS? Tot watter mate het die TAC burgers in staat gestel om deel te neem in die dag-tot-dag sake met betrekking tot die siekte, en tot watter mate het dit nie?

Sleutelwoorde: Siviele samelewing, demokrasie, burgerskap, politieke deelname, neo-liberale, VIGS aktivisme, die ‘Treatment Action Campaign,’ die Suid-Afrikaanse regering, die politiek van MIV/VIGS, Thabo Mbeki.

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Introduction

On the day of April 27, 2004, the Union buildings of Pretoria hosted the inauguration of the re-elected South African president, Thabo Mbeki. Attended by some 45 000 people, 40 presidents, ten prime ministers, a handful of royals and other distinguished international guests, and with a number of elaborate and costly festivities offered as entertainment, the inauguration fulfilled its promise to be a grandiose, if not, a majestic event. The magnitude of the presidential inauguration may have seemed somewhat pretentious if not for the fact that a celebration of another kind was concurrently taking place. That day South Africans also gathered at the Union buildings to commemorate a decade of democracy since the country's first multi-racial elections in 1994. Several months prior to the celebrations, much publicity, in the form of discussion panels, academic literature, lecture series, newspaper editorials, and daily commentaries, had been devoted to the ten-year landmark. It is as if a decade seems to have held some sort of a symbolic importance for many, perhaps signifying for some just how far this country had come, a testament to the progress made despite the odds stacked against a successful transition to democracy; or, perhaps reminding others that it was only a relatively short time ago that democracy was at best an ideal smothered beneath the reality of apartheid.

It is interesting to note that in the midst of the anniversary celebrations an important component in the eventual transition to democracy was hardly given any attention: the historical force that had brought the demand for political freedom and enfranchisement to the doorstep of the apartheid regime – civil society. In the period prior to the transition, an assortment of civic organisations, grassroots committees and social movements had united under the name of the liberation movement. Formally categorised under the term civil society, the active and confrontational nature of the liberation movement in the 1980s was considered to be one of the principle contributing factors in the eventual collapse of apartheid in 1990. For this very reason, civil society was considered to be a democratising force in itself and was thus foreseen to play a significant role in the consolidation of democracy in post-apartheid South Africa. Unfortunately, it became apparent as the 1990s drew to a close that civil society could not meet this expectation. Save for a select group of academics intent on tracing its demise, the potential importance of civil society gradually faded into the background of the public arena for a variety of

reasons outlined elsewhere in the academic literature (Johnson, 2002; Neocosmos, 1999, 1996; Kotze, 1998).

In October 2000, an unknown AIDS activist organisation calling itself the Treatment Action Campaign (TAC) reversed this trend. Having illegally imported (from Thailand) a drug used to treat AIDS related infections, and then subsequently distributing it free of charge to those in need of it, the organisation immediately attracted media interest and garnered public praise. Soon afterwards the TAC forced the pharmaceutical industry to lower the costs of anti-HIV drugs; later in 2001 it then compelled the South African government to implement a program making such medication available at public health facilities across the country. By 2002 the TAC was proclaimed in the media and academia to have reinvigorated the idea of civil society and the spirit of democracy in the post-apartheid context, and thus bring to the political spectrum a kind of activism that was once witnessed in the liberation movement (of the 1980s). In 2004, the TAC was honoured with a Nobel prize nomination for its efforts in campaigning to make affordable and even free HIV medication available to people living with HIV/AIDS in South Africa.[1]

Anybody familiar with the terrain of politics in this country over the last few years will know that the HIV/AIDS epidemic has been a highly politicised and sensationalised issue. The epidemiology of the disease is perhaps a clue as to why it has generated such fervent levels of public interest and debate. The incidence of HIV infections among South Africans are said to be among the highest in the world, with over 1 million having died from AIDS-related causes, and another 6 million forecast to die by the year 2010 (Lewis, 2004). With so much at stake, the unmanageable AIDS crisis has prompted disagreement as to the most appropriate and effective responses to the epidemic. Two conflicting positions can be located at the centre of this disagreement: one of these is represented by the South African government, the other by the TAC.

[1] HIV is the abbreviation for Human Immunodeficiency Virus; AIDS is the abbreviation for Auto-Immune Deficiency Syndrome. AIDS is caused by a group of related retroviruses known as HIV. The HI virus differs from other viruses in that it has a RNA stage and a special enzyme called reverse transcriptase. HIV targets specific T-lymphocyte cells, also known as CD4 or helper T-cells. T-lymphocyte cells help stimulate the activity of B-lymphocytes, otherwise known as CD8 cells, responsible for producing antibodies. Thus, the HI virus destroys the cells necessary for combating invading pathogenic organisms (Mader, 1998).

The South African government's response to the HIV/AIDS epidemic is a unique and ambiguous one: unique in this sense because it has attempted to approach the epidemic from a perspective that is at odds with the dominant and hegemonic biomedical discourse of HIV/AIDS; ambiguous because it has failed to spell out this position with clarity and decisiveness, sometimes flirting with the dismissal of the dominant biomedical perspective and on other occasions espousing its tenets unreservedly. It would be difficult to show that the government has possessed at any stage a unified and definitive position on HIV/AIDS and its treatment, one in which the ideological and logistical imperatives of a treatment program have been aligned and forthrightly stated.[2] The government has sought a response to the HIV/AIDS epidemic in terms of a broader socio-economic, or, it can be argued, nationalist perspective. Here, the government has understood the theory of HIV/AIDS and antiretroviral (ARV) treatment to be a product of a Western scientific paradigm at odds with, and even patronising towards the African experience.[3] The government has understood the AIDS epidemic to be a consequence of African-specific conditions, particularly poverty, inequality, poor sanitation, unemployment and other cultural factors in the spread of HIV (ANC, 2001a). Though the government has inadequately communicated its position on this matter, it has thus nevertheless attempted to raise the broader socio-economic issues of the disease. It is for this reason, then, that the government has rejected 'the notion that dealing with HIV/AIDS is only about antiretrovirals' (government spokesman in *Business Day*, 13 February 2004).

The government's HIV/AIDS policy has been opposed by a position represented primarily by the TAC along with the media, academia, and the scientific and medical community. The TAC is an organisation of civil society that has argued that the most

[2] It is also unclear as to whether this country's HIV/AIDS policy has been a product of the South African government, the ruling party of the African National Congress (ANC), or the president of South Africa and the ANC, Thabo Mbeki. It would be incorrect to claim that the South African government has been unanimous on the issue of HIV/AIDS treatment. Parliament committees and opposition parties in government have openly rejected Mbeki's (and the ANC's) position on HIV/AIDS (*Citizen*, 8 February, 2002; *Business Day*, 15 November 2001; *Sunday Times*, 7 October 2001a; *Sunday Times*, 7 October 2001b). Nevertheless, the ANC's policy on HIV/AIDS is the official government policy, and for this reason the 'South African government' (or simply, 'the government') is used throughout the course of this study to describe the 'maker' and 'shaper' of this country's HIV/AIDS treatment policy.

[3] Antiretrovirals are a sophisticated series of drugs designed to directly inhibit the rate of replication of the HI virus. There are currently 4 major classes of antiretroviral drugs in general use: nucleoside analogue reverse transcriptase inhibitors (NRTIs), nonnucleoside reverse transcriptase inhibitors (NNRTIs), protease inhibitors (PIs), and fusion inhibitors (Peiperl & Coffey, 2004).

effective response to the AIDS epidemic be positioned within the parameters of a scientific discourse advocating the use and availability of highly advanced and sophisticated medication. The TAC has thus endeavoured to bring the government's position in alignment with the scientific and biomedical expertise of the disease by demanding that it devise and implement a program making treatment and medication available to 1) HIV-positive pregnant mothers and 2) eventually to all people living with the HIV/AIDS in South Africa. In face of the government's reluctance to accede to these demands, the TAC employed a number of initiatives designed to force it to reverse its position on HIV/AIDS. The most effective of these initiatives consisted of a series of mass civil disobedience campaigns and litigation. In August 2003, as a result of intensifying public pressure brought about primarily by the TAC, the government announced that it would implement a countrywide treatment program providing ARV medication (South African Government, 2003b). In the month of February 2004, South Africans living with HIV/AIDS arrived at public health facilities to register for the provision of ARV medication at the expense of the state.

The ostensible reversal of the government's position on HIV/AIDS as well as its commitment to implement an ARV rollout program was interpreted by commentators in the media and academia as a victory for civil society and democracy in post-apartheid South Africa. The *Sunday Independent* (21 April 2002) proclaimed the 'about-turn' to be the 'dawning of reason on HIV/AIDS policy' while the *Sunday Times* (21 April 2002) boldly claimed the event to be the 'maturing' of this country's new democracy. The paper further indicated that the government was indeed susceptible to the popular opinion of its citizens, and that it could be successfully pressured to reform contentious policy – 'a sign that our civil society, which seemed to have gone in disarray when the apartheid enemy died, still has some clout' (*Sunday Times*, 21 April 2002). The *City Press* (16 December 2001) commented that the TAC's 'victory' was an example of how citizens could 'use the law to enforce rights entrenched in the constitution.' These rights were advanced by African National Congress (ANC) representatives who understood that democracy would be empty, despite the universal right to vote, if numbers of people were left to live their lives in the face of extreme social inequalities (*Business Day*, 25 January 2002). On an academic note, the TAC's socio-economic rights-based approach was interpreted as a

'stunning victory' for civil society (Jones, 2003: 18) while the nature of its confrontational stance towards the government was seen to have contributed to the advancement of pluralism (and hence democracy) in the country (Habib, 2003).

The 'success' of the TAC in compelling the government to reform its HIV/AIDS policy was understood by the media and academia to re-invigorate the importance and influence of civil society in the post-apartheid context. More specifically, the TAC was seen to have confronted the government in the name of a rights-based approach with the purpose of enabling HIV-positive South Africans to access ARV medication. It is argued in this study that this particular understanding of the TAC's 'success' derives from a theoretical framework – referred to as a neo-liberal perspective – that defines civil society as a body of private actors freely pursuing their interests and goals, without any interference from the state, on the one hand, and in the expectation that the state ensures the conditions necessary for the former to exercise a number of civil, social and political rights, on the other hand.[4] An important by-product of this formulation is that a noticeable conceptual boundary becomes drawn between the state and civil society, where the former is seen to be the domain of power and where civil society is seen to balance, curb, influence and monitor the power of the state. From this perspective, civil society comes to be understood in terms of its structural properties in relation to the state, in other words, as a 'plurality' of associations, or organisations and social movements; as the 'non-profit' or 'non-government' (NGO) sector, as a 'watchdog' of civil, social or political rights (by ensuring that the state does not interfere with these rights in any manner), or as a 'counter-weight' to the power of the state, and so on.

In this study it is argued that a neo-liberal perspective is limited in its theoretical formulation of civil society, and as a result provides an inadequate understanding of the

[4] The term 'neo-liberal' is often used in to describe an economic philosophy which came to prominence in the 1980s under the governmental policies of Ronald Reagan (United States President) and Margaret Thatcher (British Prime Minister). Alternatively referred to as the 'Washington Consensus', neoliberalism advocates a minimalist role of the state and/or the government in the affairs of the marketplace in the expectation that global progress, social justice and socio-economic development can be realised by free trade and capitalism. In this study, a neo-liberal perspective is used in a political context to refer to an understanding of civil society that draws a similar conceptual division between the state and civil society. It is necessary here, however, to draw a distinction between a neo-liberal perspective of civil society and the philosophical tradition of classical-liberalism. Though deriving many of its principle theoretical tenets from this tradition, a neo-liberal perspective of civil society is bound to the historical period following the collapse of the popular organisations and social movements towards the close of the 1980s.

TAC's 'success'. Here, it is suggested that the meaning of civil society carries a greater conceptual weight than what a neo-liberal perspective has assigned to it. Considering that some of the most prominent Western thinkers since Aristotle have devoted their attention to the term, it is strongly asserted that civil society embodies an idea that is more significant than its neo-liberal characterisation as a guardian of state power, or as the non-profit or non-government sector, or as a realm comprising a plurality of associational relations (such as 'stokvel' partnerships or soccer committee's, and so on). These structural descriptions may serve to illustrate what a civil society consists of, but they explain neither the meaning nor the purpose of civil society in a satisfactory manner. In Chapter 1, then, an attempt is made to advance a more adequate understanding of civil society by introducing an alternative theoretical orientation. Drawing from the political thinkers of the ancient Greek states, where the concept was thought to have originated (at least from a Western perspective), a popular-democratic perspective of civil society can be understood as a realm of activity in which citizens endeavour to substantiate their lives as social and political beings. This understanding also emphasises the capacity of citizens to participate in the public affairs of the state while simultaneously undertaking to remove the locus of political activity away from the state, and thereby influence important social and political issues that have an affect on a citizen's day-to-day affairs.[5] As discussed in Chapter 1, this perspective of civil society was witnessed most vividly in the 1980s as popular organisations and social movements in Eastern Europe, Africa and Latin America mobilised and organised to reconfigure the existing structures of the public realm and therefore bring about social, economic and political reform in the name of democracy.

It is upon this theoretical argument that the research methodology of this study is based. Here, a case analysis of the confrontation between the TAC and the South African government is presented in an attempt to advance a popular-democratic perspective of civil society. It is expected that the selected case will reveal the limitations of a neoliberal perspective of civil society, from which popular interpretations of the TAC's 'success', as

[5] It is for this reason that a critical discussion a neo-liberal perspective, rather than the liberal tradition in its entirety, is presented, since some classical-liberal thinkers such as Jean-Jacques Rousseau and Stuart Mill did much to expand on this popular-democratic vision of civil society.

represented in the press and the academic literature (described above), have emerged. It is further hoped that this study can, in some way, contribute to an already existing (yet inadequate) understanding of state-civil society relations in the post-apartheid context. In Chapter 2, then, the study's research aim, the selection of the case, and the use of research methods are all discussed at a more appropriate length.

In Chapter 3 an analysis of the TAC commences with particular emphasis being placed on the organisation's ability to enable the participation of citizens in a key public health issue. It is suggested that the reluctance of the South African government to make ARV medication available at public health facilities countrywide directly affected the manner in which people living with HIV/AIDS could manage and direct their daily affairs. In this respect, citizens were 'demobilised' as government politicians undertook to implement, what they believed, was the correct and appropriate HIV/AIDS treatment program. Thus, for a long period of time, the government proceeded to make health decisions on behalf of citizens and people living with HIV/AIDS – regardless of the their demands for the access to ARV medication. In response, citizens, under the banner of the TAC, mobilised and organised to influence the government's position on ARV treatment. Of the various strategies employed by the TAC, three of the most effective are selected and described in more detail. Summarised briefly, these consist of 1) the organisation's civil disobedience campaigns, which permitted citizens to actively protest the government's treatment policy; 2) the organisation's treatment literacy campaign, which has endeavoured to empower citizens by educating them about important HIV/AIDS issues; and 3) the organisation's community based branches, which have enabled the institutional participation of citizens in the local decision-making processes of the treatment and management of HIV/AIDS.

At first glance, the story of the TAC is in many respects similar to that of the early AIDS activist movement in the United States, which demonstrated the popular-democratic character of civil society in the early 1980s. Here, vocal and active movements and organisations of civil society sought to confront the apathetic response of both the medical community and the United States government – termed by activists as the 'AIDS establishment' – to the increasing threat of an AIDS epidemic in that country. Realising that much stigma and discrimination towards people living with HIV/AIDS

existed, activist movements and organisations sought to confront the AIDS establishment by way of a number of strategic initiatives. Significantly, organisations such as ACT-UP (AIDS Coalition to Unleash Power) called for the self-education and participation of activists in the social construction of the disease as well as in the medical development of its treatment. These strategic initiatives employed in the United States during the 1980s are familiar to AIDS activists in South Africa, and it is for this reason that a brief review of that historical period is offered prior to the proceeding discussion of the TAC.

A popular-democratic perspective of civil society, as is reviewed in Chapter 1 and employed as a framework of analysis in Chapter 3, is further extended into Chapter 4. It is at this juncture, however, that a more critical analysis of the TAC's 'success' is presented.[6] As already mentioned, the central argument of this study is based on the perspective that the term civil society can alternatively be understood as a realm enabling the idea of an active citizenship, where citizens continually partake in the public affairs of the state in the effort to substantiate their lives as social and political beings. Chapter 4 once again takes up on this theoretical idea by resuming a discussion of the AIDS activist movement in the United States. In many respects, American activists were acutely aware of the prevailing AIDS discourses that were in operation at the onset of the epidemic. For the most part, these discourses sought to marginalise people living with AIDS, while at the same time prevent the general public from accessing the relevant knowledge available at the time about the disease. One of the major initiatives witnessed in the period of the 1980s was the progressive effort to open up the insulated sphere of science and medicine of HIV/AIDS to the general public. This initiative to 'democratise' science was seen as an attempt to empower citizens with the capacity to partake in the processes by which HIV/AIDS disease was understood and treated.

Though it is not suggested that a simplistic comparison be drawn between the American and South African contexts, it is nevertheless useful to consider both side by side. In South Africa, a similar confrontation has been witnessed between the AIDS movement (represented primarily by the TAC) and the 'AIDS establishment' (in this

[6] It is for this reason, then, that the TAC's 'success' is placed in scare quotes: as a means to alert the reader to the fact that it is a continually contested point of analysis and interpretation throughout the course of this study.

case, the government). A highly sensationalised and public debate concerning the science of the disease has also taken place, while two prominent discourses have underlined the conflicting positions of the debate itself. In Chapter 4 these two discursive positions are explored in greater detail; the central argument, here, being that that the TAC has adopted an agenda that is contrary to a popular-democratic vision of civil society. It is put forward that the organisation has campaigned to insulate the sphere of science and medicine from the general public, and it has counteracted swiftly any attempts to challenge or question the dominant discourse of HIV/AIDS itself. It is for this reason that the term 'discourse', as Foucault understood it, (McHoul & Grace, 1993) is introduced in this study: as a tool to deconstruct the politics of HIV/AIDS in South Africa, and thereby demonstrate from a popular-democratic perspective how the capacity for citizens to participate in public health issues related to HIV/AIDS may yet to be realised even in light of the TAC's 'success'. This observation serves as an entry point from which a number of similar and critical questions can be asked, questions which are all the more prominent when situated in the context of what Hopkins (2002a) refers to as a 'post-TAC society' – a context in which the politics of HIV/AIDS treatment becomes reconfigured in response to the government's decision to reverse its position on HIV treatment. Now that an ARV rollout program is in operation, it is asked how citizens are to mobilise and organise their activities so as to maintain some sense of agency when having to confront the day-to-day realities of the HIV/AIDS disease? Will citizens continue to actively participate in HIV/AIDS treatment issues, or will citizens simply become passive subjects in the political, social and economic contexts of their lives? What effects will the government's ARV rollout program have with regards to the idea of an active citizenship? Does the availability of ARV medication mean that citizens will be empowered to direct and take control of their daily affairs?

The answers to these questions are not evident or straightforward, and it should be acknowledged here that this study does not set out to resolve them either. What this study does attempt to do, rather, is to convince the reader that these questions can only emerge once a popular-democratic perspective forms the basis of an understanding of civil society. This is because the theoretical nature of a neo-liberal perspective is such that it cannot begin to address the questions listed above adequately, let alone conceive of them

in the first place. Because of this theoretical deficiency, the 'success' of the TAC has been popularised as well as sensationalised by the media and academia to the extent that it has overlooked a much-needed critical and objective analysis of the politics of HIV/AIDS in this country. As a result, the following chapter will immediately turn to the term civil society in an attempt to advance a theoretical perspective that will hopefully undercut these particular shortcomings.

Chapter 1: Two Perspectives of Civil society

1. Introduction

One of the foremost sociologists, John Keane (1998: 36), claims that the concept 'civil society' is much like a 'catchy advertising slogan' – played over and over again that it 'risks imploding through overuse'. Though not denying its significance, Keane is suggesting that the recent revival of the concept has generated a great deal of attention, so much so that the former has been left with a multiplicity of competing meanings. In many respects, civil society has become conceptually indeterminate, successfully evading the intellectual endeavour to ground the term within a single and unifying theoretical framework. In this respect, pinning down a definitive understanding of civil society has been a source of frustration and disagreement for scholars of particular political and social scientific orientations. For some, civil society is the coloniser, the bourgeoisie or the frontline; for others, it is the new hope, the new liberation, or the final salvation.

If we are to briefly set aside these conceptual differences, Seligman (1995: x) has claimed that the concept 'civil society' can be seen to envisage some sort of an 'ethical ideal of the social order'. Seligman's claim is as much correct as it is broad. If one stretches this formulation of civil society to such an extent, then the concept can be understood as something of a panacea, at least from a historical juncture where it has resurfaced at times of social disorder and transformation. As Gibbon (1990: 30) informs us, the striking feature of the emergence of civil society in various historical contexts arose 'in relation to the defeat of some major socio-political project'. This was readily apparent in the work of Locke following the eventual disintegration of the feudal order and the emergence of the modern nation-state, in the Scottish Enlightenment thinkers at the burgeoning of commercial society, in Hegel following the French revolution, in Marx during the Industrial Revolution, in Michnik *et al* during the Polish uprisings of 1980-82, with the collapse of single-party regimes in post-colonial Africa, and in the transition from apartheid to a democratic South Africa. In these cases, the idea of civil society was evoked for the purposes of formulating the political, civil and ethical relations between members of a community (citizens) and the higher political authority of that given social order (the state).

After a somewhat lengthy absence as a useful philosophical and political concept, the term civil society made its return to the intellectual fore in the 1980s. It was in this period that debates were re-invigorated as to the precise conceptual meaning of civil society. With the collapse of the communist state in Eastern Europe, and the apparent decline of patrimonial and one-party states in Africa, as well as the fall of military regimes in Asia and Latin America, a renewed focus turned to the influential role of civil society in emerging democracies. In the geo-political contexts of Poland and South Africa (as two selected examples of the East and the South respectively), a popular-democratic vision of civil society was resurrected. Particularly in the 1980s, organisations and movements of civil society were considered to have played an integral part in bringing about and consolidating social and democratic reform. In these instances a sense of political participation and awareness was heightened as people sought to confront an authoritarian state that reduced the idea citizenship to a repository of passive subjects – as opposed to a community of active citizens. Here, subjects mobilised to demand for the re-instatement of a space where they could proceed to substantiate their social existence by actively partaking in the public affairs of the state. Thus, subjects endeavoured to actively determine the affairs of their lives, which had, until the historical moment of liberation, been the prerogative of the authoritarian state. It is for this reason, then, that organisations and movements in the struggle for social reform were seen to bring about 'renewed enthusiasm' for the power of civil society in emerging democracies (Zuern, 2000: 96; Ndegwa, 1996).

In Poland, the re-emergence of a popular-democratic perspective of civil society was witnessed in the organisation and mobilisation of social movements against the repressive nature of the Socialist party-state.[7] Here, an intrusive state sought to override independent centres of public power by either incorporating them into the bureaucratic structures of the ruling party, or by outright suppression and banishment. In response, social movements and organisations of civil society endeavoured to carve out 'autonomous and legally sanctioned spheres of activity' (Zuern, 2000: 95) by pushing back 'state-

[7] Though the spirit of Polish resistance had been present in the community psyche since at least the Warsaw rising of 1944, there was a distinguishing quality about these movements, particularly that of Solidarity and the Social Self-Defence Committee (KSS-KOR), that ushered a return of faith to the idea of civil society in playing a significant role in its given political and social order.

administrative forms of penetration from the various dimensions of social life' (Cohen & Arato, 1995: 32).[8] As a result, prominent organisations such as the Solidarity Movement and the Social Self-Defence Committee (KSS-KOR) sought to bring about the 'legal and institutional realisation' of civil society within the 'existing structure of the state' (Arato, 1981: 34).[9] In this respect, the emerging prominence of civil society as a realm of political activity in Poland was the product of the collective will of citizens to liberate themselves from state control while seizing the opportunity to redeem Western notions of democracy in their demands for civil liberties, workers rights, a free press, free elections, an independent judiciary, and so on (Touraine, 1983).

In South Africa, a similar process was under way in the 1980s. Here, civil society was seen to be a realm of activity housing a number of civic organisations, grassroots committees and social movements all united under the banner of a mass liberation movement. And, much like the historical and political contexts of the East, these organisations and movements sought to regain some of the space that had then been 'occupied almost exclusively by the apartheid state' (Shubane, 1995: 68). An important feature of the liberation movement in South Africa was the nature of the peoples' struggle for power. In an attempt to reconfigure the relations of power under apartheid, subjects collectivised to create alternative structures of organisation and control. As Johnson (2002: 5) explains:

> these popular-democratic groups sought to challenge the very basis of state politics and state power, and in the process redefine the relations between state and society, between ruler and ruled. By developing alternative structures of power and government, these popular democratic organisations developed the seeds of an

[8] A new perspective of civil society, thus, appeared in the theoretical conclusions drawn by Michnik of two historically significant events: in Hungary, 1956, and Czechoslovakia, 1968. Michnik (1981) in response to these events sought to provide the theoretical elaborations for the failure of social and political change from the periphery and from the centre: as in the failure of revolution from below (Hungary, 1956); and the inability of state to reform from above (Czechoslovakia, 1968).

[9] As Kuron, a prominent spokesman of KSS-KOR, on a question of social reform in Poland pointed out: 'It is a matter of a system in which the social structure can be established from below, while the decisions of principle are coordinated with the central authorities of the communist party' (Kuron, 1982: 95).

'emancipatory politics', revolutionary, liberating, progressive, and fundamentally rooted in the masses of the people.

The rapid development of civic organisations, labour unions, street committees, student organisations, crisis committees and so on, in the mid 1980's was a direct expression of what was often referred to as the 'organs of people's power' (Mashamba in Nzimande & Sikhosana, 1995: 49). But essentially, a complete seizure of state power was the overriding objective of the liberation movement since the implicit belief was held that the everyday conditions of people would be transformed to the point where they could take control of their daily activities. Not only were these organs of people's power concerned with opposing the racist policies of apartheid, they were also fundamentally concerned with 'extending the sphere of freedom' as well as 'extending the field of engagement for people outside the state' (Shubane, 1995: 69). In this respect organisations of civil society came to embody a form of 'popular politics' in which disenfranchised subjects of an illegitimate state collectivised to bring about a democratic social order. Here, organisations and movements from 'below' struggled to bring about a condition where political activity could legitimately take place. Thus, the liberation movement endeavoured to bring about a social or political space in which 'subjects' became 'citizens' and where these 'citizens' could become active agents in the daily affairs of their lives.

2. Civil Society and Citizenship: A Popular-Democratic Perspective

The success of the Solidarity movement in Poland, in its earliest opposition to the socialist party-state in 1976, and the eventual appointment of its leader, Lech Walesa, to the presidency in 1990, orientated a good deal of academic attention to the precise role and importance of civil society in emerging democracies. Debates on the role and the conceptualisation of civil society in Africa were also invigorated in the early 1990s by a notable return to multi-party democracy. By 1994, remarkably, not one of the 29 countries that were governed (5 years previously) by single- or no-party states remained (Southall, 2003; Huntington, 1991). Civil society was seen to be at the 'cutting edge' of

the progression towards a 'viable democratic order' (Diamond, Linz, & Lipset, 1988: 26), and as a result, was foreseen to push the transition to democracy through to completion (Diamond, Plattner, Chu & Tien, 1997: xxx). Because of its prominent role played in the democratisation process, civil society came to be conceptually coupled with the notion of democracy in the effort to explain the nature of modern political society in post-Africa, prompting some scholars to dismiss both terms on the basis that they have become popular political buzzwords without substance or meaning (Zuern, 2000).

The tendency with the observation described above, as Kotze (1998: 83) has pointed out, is that 'civil society has come to be widely perceived as both a prerequisite and a symptom of a well functioning democracy'. This complex conceptual coupling can be better understood if the historical and theoretical lineages of both terms are traced. The origins of the term civil society can be found in the political and intellectual tradition of the Ancient Greeks. Taken from the Greek, *politike koinonia* (political community), from which the Latin *societas civilis* derives, civil society was understood to be a realm enabling the participation of citizens in the process of rule and government. In this tradition the notion of democracy was closely, if not inextricably, linked with idea of civil society. *Demokratia*, meaning rule (*kratos*) by the people (*demos*), was first thought to have been institutionalised in the powerful city-state of Athens in the two centuries from 500-300B.C. It was essentially in the Athenian city-state that a new and radical politics was envisaged, where the participation of citizens in the process of government truly separated the idea of democracy from the alternative political models of rule by monarchy and oligarchy. As Held (1995: 6) explains:

> citizens were at one and the same time subjects of political authority and the creators of public rules and regulations. The people engaged in legislative and judicial functions, for the Athenian concept of citizenship entailed their taking share in these functions, participating directly in the affairs of the 'state'.

In ancient Greece the idea of democracy in its earliest form thus became associated with the participation of citizens in the public and political institutions of the state, or

more correctly, the *polis*. Hence, the Greek definition of democracy as the 'political power wielded actively and collectively by the *demos*' (Ober, 1996: 19). As is consistent with this definition, democracy was understood to be a condition that enabled citizens to interact individually with one another, on the one hand, while simultaneously participating in the process of rule or government, on the other. In such a political order men of all classes actively engaged as equals in the democratic institutions of the people's courts and assemblies. This implication meant that that the political processes and institutions of ancient Greece were not simply limited to the rank of the ruling elite. Democracy, therefore, was a political condition open to the participation of citizens (women, slaves and foreigners did not possess citizenship status) in the public affairs of the *polis*.[10]

The emphasis placed by the ancient Greeks on the role of participation should not be understated. As Roberts (1994: 42) points out: the essence of this participation was 'the presence of a vital force drawing each [male] heart and mind into both deliberation and action… a virtue lacking under other constitutions.' In Greek political thought, action (*praxis*), together with speech (*lexis*) were the two human activities constituting, in Aristotle's terms, man's status as a *zôon politikon.* In the words of Hannah Arendt (1958: 7), the human activity of action was considered to be 'specifically *the* condition of all political life'. And speech, or public speaking (*logos*), was a mode of political action that enabled the *demos* the possibility of partaking in the democratic institutions of the *polis*. As a result Athenian democratic institutions, for example, were structured in such a way that the people 'maintained their rule through [the] control of public speech' (Ober, J. 1996: 20.

[10] This model of Greek democracy is intended to forward the more abstract idea of a popular-democratic idea of civil society. It would be misguided to suggest that such a model could be replicated and incorporated (in its entirety) into the institutional structures of the modern day nation-state. Though, this admission should not justify its wholesale dismissal, rather, it should be acknowledged that alternatives to a neo-liberal perspective exist and that they can be developed to the extent that they become feasible political systems or projects to be considered at moments of social crisis and transition. A point should also be made with regards to the parenthesis of the historical fact that women could not partake in such democratic settings. This observation was documented in order to reveal one particular shortcoming of the Greek model and in no way suggests that the historical disenfranchisement of women should be transported into the modern era. It is however acknowledged that this study does not consider in any manner the problematic sociological question of how gender (inequality) continues to structure contemporary ideas of citizenship – a complex debate which understandably falls beyond the theoretical scope of this study.

As with the terms civil society and democracy, the idea of citizenship can also be traced back to the Ancient Greeks. In this historical period, a 'citizen' was someone who belonged to a specific political community and who possessed the right to participate in the public realm of the state. According to Eriksen & Weigard (2000: 15) this particular form of membership entailed a 'responsibility' or an 'obligation' to the community, a duty, so to speak, that was undertaken with pride and honour. In this respect, the participation of citizens in the day-to-day affairs of the public realm was considered to be a moral or virtuous act in itself, and it was, in the view of Aristotle, one of the primary means to achieving a morally excellent life (Flathman, 1995). It is for this reason, then, that the idea of political participation was taken so seriously by the Greeks. To be an active citizen meant the process whereby one constituted the fabric of his existence, as 'no human being could be themselves without participating in public life' (Crick, 2000: 4).

3. Perspectives of Civil Society after Antiquity

Until its re-emergence in the late 20th century, this perspective of civil society was vanquished to antiquity following the collapse of the ancient Greek states. Though initiated by the decline of that civilisation, changing historical and theoretical understandings of citizenship accelerated the diminishing importance of a popular-democratic vision of civil society. Following the Greeks, the idea of citizenship came to mean something quite different to what had so far been formulated. In the thought of Aristotle and the ancient Greeks, citizens subordinated their private interests to the shared recognition and pursuit of the public good, since it was in the public arena, and not the private realm of the household (which was concerned with the reproduction of material consumption) that a citizen could fulfil a meaningful existence. It was only through the participation in civil society – which was considered to be more of an obligation than a choice – that a person could be a 'true' or 'active' citizen. In the Roman era this idea of citizenship came to be reformulated, where a citizen became defined in legal terms rather than in terms of his political actions. As Pocock (1995: 35-36) notes:

> The individual thus became a citizen – and the word 'citizen' diverged increasingly from its Aristotelian significance – through the possession of things and the practice of jurisprudence. His actions were in the first instance directed at things and at other persons through the medium of things; in the second instance, they were actions he took, or others took in respect of him, at law… His relation to things was regulated by law, and his actions were performed in respect either of things or of the law regulating actions. A 'citizen' came to mean someone free to act by law, free to ask and expect the law's protection, a citizen of such and such a legal community of such and such a legal standing in that community.

Whereas a Greek citizen was someone who participated in the formulation of the laws by which he was governed, a Roman citizen was simply subject to the law which regulated his rights and entitlements. Some centuries later in the historical period of early modern England, this idea of citizenship was extended to mean free status. And, the rights attached to that status were called 'civic' or 'civil' rights', which included amongst others 'the right to own property and to make valid contracts, the right to sue in court…freedom of speech, thought and religious faith' (Fraser & Gordon, 1994: 95).

This understanding of citizenship and civil rights was championed in the Enlightenment period for the most part by the English philosopher John Locke. As did his counterpart before him, Thomas Hobbes, Locke employed the notion of a 'state of nature' as a means to theorising a social or political order in which the liberties of men could be fully realised and protected. According to Locke, the law of nature granted man not only his freedom but also the right to pursue his own interests, so long as this pursuit did not infringe upon the rights of others. In practice, however, the condition of a state of nature was unstable since human interests were likely to collide and collapse into conflict. This problem would be further compounded by the fact that men were fairly erratic and fallible agents of justice and penalty. These are the 'inconveniences of a state of nature' that Locke (1924) refers to throughout his *Two Treatise of Government*. According to Dunn (2001: 51), Locke saw the idea of civil society as a 'historical remedy' for the 'inconveniences of a state of nature'. Here, Locke envisaged a social

realm in which citizens joined collectively to form a 'social contract'.[11] From this social contract the idea of civil society would emerge to guarantee and protect an individual's right to private property, freedom and equality (Lloyd Thomas, 2002). However, in order to manage the conflicts of citizens in their pursuit for individual interests or goods, it was necessary to establish an independent but accountable legal arbitrator. At this point, the idea of the state, which Locke calls a government, and what Hobbes would refer to as the 'Leviathan', was formulated to arbitrate and regulate the actions of men and women in contract with one another. It is interesting to note, though, that both Hobbes and Locke initially conceived the state to be 'a necessary evil' whose purpose was to protect and enhance the private freedoms of its citizens (Ignatieff, 1995: 53). For this reason, then, civil liberties became subsequently incorporated into a framework of law protecting citizens against the potentially intrusive nature of the nation-state (Crick, 2000). In this respect, the concept 'civil society', from as early as the classical-liberal tradition, came to be defined as an autonomous and independent realm in relation to the state.

Following Locke, the Scottish Enlightenment philosophers (Hume, Smith, Ferguson and Hutcheson) similarly attempted to formulate an idea of civil society that would accommodate the increasing 're-organisation of social life around a modern sovereign state' (Khilnani, 2001: 6). The latter thinkers endeavoured to synthesise a number of conceptual dichotomies that had begun to emerge between the individual and the society, the private and the public, and acts of egoism and altruism. Here, the idea of civil society as put forward by the Scottish Enlightenment thinkers was the attempt to construct, in paraphrasing Seligman (1995: 31), a social order set out to overcome these sets of oppositions. The solution for the Scottish philosophers was thus to place the value of civil society 'in the economy, in property rights and markets where such rights [could] be freely exchanged' (Khilnani, 2001: 13). Therefore, Hume and Smith, in following Locke's notions of civil freedom, theorised a new economic polity in which a community of individuals could pursue their own multiple private interests while remaining

[11] This contract would function to establish a social realm in which men could enjoy the full yet reasonable extent of their natural rights. To do so, however, each man would first have to forego a number of certain rights, for example the right to exercise justice and penalty. These rights would then be passed on an 'appointed government' whose duty would be to ensure the administration and prescription of justice and penalty (Locke, 1924: II. 13).

enveloped in the interests of public welfare; Hutcheson attempted to support a 'collective notion of the common good' on a theory of individual moral sense; and Ferguson's equation of civil society as the good state signified 'a polity of active citizens' who were able to benefit from the wealth they accrued while availing themselves of their sense of personal importance (Oz-Salzberger: 62, 75).[12]

4. State-Civil Society Relations: Towards a Critique of a Neo-liberal Perspective

It is argued in this study that the classical-liberal framework described above forms the foundation of a neo-liberal perspective of civil society. Drawing from the work of Locke and the Scottish philosophers as its theoretical base, a neo-liberal perspective tends to define civil society as a body of private actors freely pursuing their interests and goals, without any interference from the state, on the one hand, and in the expectation that the state ensures the conditions necessary for the former to exercise these civil, social and political rights, on the other hand (Den Uyle, 2000; Boxx & Quinlivan, 2000; Janoski, 1998; Delue, 1997). Civil society, in this manner, is situated independently in relation to the state, while simultaneously possessing the capacity to place demands upon the state itself. An important by-product of this formulation is that a noticeable conceptual boundary becomes drawn between the state and civil society, and as a result, the former comes to be understood in terms of its structural properties in relation to the latter. In contemporary social science theory, this perspective tends to dominate formulations of civil society. For example, Drah (1995: 17-18) considers civil society to be 'the presence of an assortment of intermediary groupings that operate in the social and political space between the primary units of society (such as individuals, nuclear and extended families, clans, ethnic groups and village units) on the one hand, and the state and its agencies on the other. Kasfir (1998: 4) considers civil society to be non-state political activity;

[12] The social tensions that had caught the attention of the Scottish philosophers was further taken up in the work of Hegel – though this thinker is not considered to belong to the classical-liberal tradition under review here. Hegel argued that civil society was the arena in which the particular interests of individuals came into conflict, and thus ultimately threatened the very realm allowing these conflicts to be expressed in the first place. Hegel's bifurcation of the state and civil society was thus a philosophical attempt to create a new space in which the ideal of subjective freedom and the pursuit of individual ends could flourish. This space, according to Hegel, would have to reside somewhere between the family structure and the state since the family as the residual category could no longer provide for the individuals 'totality of needs' in the modern world (Jones, 2001: 121).

Bratton (1994: 56) sees it as the 'political activity between [the] government and family', while Hawthorne (2001: 269) associates civil society with 'a lively associational realm between state and family'. Diamond (1999: 221) defines civil society as 'an intermediary phenomenon, standing between the private sphere and the state'; while Cohen & Arato (1995: 74) inform us that the 'common core of all interpretations' consider civil society to be 'a sphere other than or even opposed to the state'.

As will be discussed in more detail below, civil society comes to be understood as a 'plurality' of associations, or organisations and social movements; as a 'watchdog' of civil, social or political rights (thus ensuring that the state does not interfere with these rights in any manner), or as a 'counter-weight' to the power of the state, and so on. In this respect, civil society functions to check up on the various state institutions and monitor the decisions of government policy and rule (Diamond, 1999). (Because, following the transition to democratic rule, it can be claimed that the measures necessary to curb corruption, ensure transparency and foster a climate of accountability would be generally lacking, since these conditions were not present under statist or authoritarian rule.) Here, civil society is understood to function as a 'watchdog' or a 'counterweight' to the state by pointing out any state inadequacies and mismanagement practices that negatively affect the community. Thus, it is considered the responsibility of civil society to bring to the public attention any form of state malpractice through various communicative channels, be it forums, public gatherings, the media, marches, rallies and so on.

Civil society further fulfils this 'counterweight' or 'watchdog' role by ensuring (sometimes by virtue of its mere existence) that power does not only remain within political parties and/or the state organs (Botha, 1992). By distributing power over a range of social organisations, the presence of civil society substitutes state centralisation with institutional pluralism. Implicit in this notion is the idea of civil society as a pluralistic or heterogeneous association or organisations, social movements, interest groups, non-governmental organisations, community based organisations, and so on. This conceptualisation has recently been extended to include a plurality of relations between the state and civil society (Habib, 2004). Thus the presence of 'pluralism', either in civil society itself or in its relation to the state, is understood to be a contributing factor to the consolidation of democracy in post-authoritarian states.

From a neo-liberal perspective, civil society also functions to 'civilise' the state by working harmoniously with it in cultivating an ethos of civility (Friedman and Reitzes, 1996: 59). To do so, Atkinson (1992: 43) argues, there must exist a mutual aspiration on the part of both the state and the individual to build a 'shared sense of community and citizenship'. Thus the civic relations between members of society and between the latter and the state are not only compelled by a legal or pre-established framework of rules, they are also guided by a sense of respect and consideration for the other (Kasfir, 1998). This entails that civil organisations eschew anti-democratic forms of behaviour and violence, and tolerate instead the views of others and the legal constraints of the state. In doing so civil society organisations become the 'nurseries of democratic practices' by submitting their internal structures and organisational processes to rigorous democratic procedures (Drah, 1995: 34). Here, for example, leaders should be democratically elected, of which this hierarchy must be subsequently accountable to its members; there should be a degree of transparency in a given organisation's structures and operations; members should be treated equally; and disagreements within the organisation be openly aired and resolved, and so on. By subscribing to the principles of democracy, civil society endeavours to foster a political culture that will oblige citizens and the state to act accordingly to one another (Kasfir, 1998).

It is for this reason that some scholars (of the political orientation under review here) have argued that during the apartheid era civil society could not possibly exist in its technical sense. This is because the nature of politics in the liberation struggle – violent and retaliatory resistance, covert anti-statist activity, political in-fighting amongst factions in opposition to the state, the state ban on political movements and organisations, and so on – could not fulfil the criteria of a neo-liberal perspective of civil society. Implicit in this assumption is the notion of a legitimate state permitting civil society to display and infuse its democratic practices within the broader political and social sphere, a condition which was visibly absent in the South African state's response to the liberation movement. Hence Shubane's (1992: 38) claim that it is only beyond a 'liberation-style politics' that civil society can legitimately be considered as an agent of democracy. Civil society from this theoretical departure emerges only once a liberal-democratic political condition has been established, which is, in other words an 'inclusive

legal constitutional framework, legal citizenship, a culture of rights and duties, formal legal equality of all individuals, a culture of political tolerance and a legitimate government' (Reitzes, 1995: 101).

5. Advancing a Popular-Democratic Perspective of Civil Society

It is argued here that the neo-liberal perspective of civil society described in the section above is inadequate. This perspective is inadequate because it fails to take into full account the significance of civil society as a realm enabling the potential of an active citizenship, that is, a realm in which citizens possess the capacity to take control and direct the public affairs that have an impact upon their lives. It is argued here that the meaning of civil society is simply more than the description of a plurality of non-profit organisations situated autonomously in relation to the state. Furthermore, this understanding of civil society as a realm established to guarantee and protect the civil rights of citizens is insufficient in its capacity to account for the significance of political activity and the idea of an active citizenship. This is because a neo-liberal perspective considers an individual to substantiate his/her social existence as a citizen when in pursuit of some private interest or goal. In addition, this understanding seems to also identify civil society as something that is defined in relation to the state but that exists autonomously of it. The separation between the state and civil society is further emphasised when the latter is conceived to decentralise power (by virtue of its plurality) and protect citizens from the advancements of the former.

As discussed in greater detail below, the conceptual division between civil society and the state has resulted in the former being conceived of as a realm devoid of the capacity for political activity.[13] In this study it is argued that such a neo-liberal formulation conceives of political activity to reside outside of the realm of civil society. Politics, from this viewpoint, is something undertaken within the domain of the state, or within the realm of a political society. In this respect, the idea of politics or the capacity for political

[13] This is not to suggest that a neo-liberal perspective considers civil society to be a non-political realm. It is the case that the boundary between the two realms is occasionally blurred – as when, for example, citizens participate in periodic voting or when the state intervenes to enforce law and order – but for the most part this separation is conceptually definitive as it is rigid.

activity assumes a particularly limited or minimalist definition. Contemporary political activity is simply reduced to the process of selecting candidates who are in competition for government office or power.[14] Here, the state makes available the apparatus for selecting political leaders, and a political society is that which consists of the parties and forces in competition for political leadership.[15] As a result, a clear division becomes drawn between the state, or a political society, on the one hand, and the broader realm of civil society, on the other. And it is in this respect that civil society is formulated to insulate citizens from the political affairs of the state, and to 'prevent [a] political society from imposing [their] collective goals and preferences upon individuals who do not share them' (Flathman, 1995: 136).

It is argued here that this neo-liberal emphasis on the division between the state and civil society becomes redundant when advancing the argument for a popular-democratic perspective. This is not to suggest that the division between the state and civil society be collapsed; rather a popular-democratic perspective advocates the idea that politics or political activity be located within the realm of civil society. Civil society, then, is considered to be a highly politicised realm in which citizens can partake in the public affairs of the state and pro-actively improve the quality of their lives. From this point of departure, an active citizenship is enabled 'in a variety of places and spaces', where the 'centre of politics' is shifted away from the state to recover 'the possibility of politics as an individual participation in a shared and communal activity' (Clark in Faulks, 2000: 10). According to Barber **(**1984: 151), an active citizenship thus relies on the act of

[14] Thus, under the banner of 'popular control of government' citizens report to the ballot boxes to cast their votes (Birch, 2002: 101), implying for Mayo (in Bachrach, 1969: 21) that 'democracy means only that the people have the opportunity of accepting or refusing the men [sic] who are to rule them'.

[15] In 1942 Joseph Schumpeter proclaimed democracy to be a method whereby political decisions were arrived at via 'a competitive struggle for the peoples vote' (Schumpeter, 1987: 269). The method of democracy, Schumpeter argued, was an end itself and not a means to an end, as for example, in realising a formulation of democracy as the common rule or will of the people. Schumpeter declared that the standard of democracy was not to be judged on the degree of centralisation or devolution of the decision-making process but rather the degree to which it conformed to the basic principles of the democratic method. In other words Schumpeter argued that the value of democracy and the success of a particular democratic system could or should not be measured on terms of its capacity to realise, say, a given set of democratic ends, whatever these may considered to be. As long as democracy as a political method maintains an open system – political equality, freedom of speech, majority rule, periodic elections, party competition, accountability of political elites to non-elites – then it can be said to have sufficiently fulfilled its function.

> participation in an evolving problem-solving community that creates public ends where there were none before by means of its own activity… In such communities, public ends are neither extrapolated from absolutes nor 'discovered' in a preexisting 'hidden consensus'. They are literally forged through the act of public participation, created through common deliberation and common action and the effect that deliberation and action have on interests, which shape change and direction when subject to these participatory processes.

It is particularly this idea of civil society that envisions politics 'not as a way of life but as a way of living' (Barber**,** 1984: 118). Politics, thus, is not the exclusive activity of the government or the state. Citizens are not simply the objects of a system in which politics is enacted upon them. In this respect, the possibility of an active citizenship thus 'reduces a sense of estrangement' from the political system in the sense that citizens are not merely passive or subordinate recipients of external political output (Held, 1996: 267). Rather, civil society can be understood as a realm which endows citizens with the confidence that their actions have a meaningful impact within the public realm. In other words, citizens are capable of interacting with political leaders and politicians in setting political agendas and making basic policy decisions. As envisioned here, civil society would invigorate citizens to actively partake in the decision-making process and choose for themselves policies that will improve the quality of their lives.

From this perspective individuals have an interest in the end results of the political process and they express this interest through the active mode of participation. This leads a citizen to experience a greater control over his/her communal life, which in turn motivates him/her to participate in other spheres of activity (Birch, 2002). A popular-democratic vision of civil society produces a knowledgeable citizenry that is capable of taking an interest in the public affairs of the state. Citizens thus contribute to a democratic culture by being informed about political issues. This particular perspective need not imply that every political issue is judged according to public opinion; humans are fallible and the public is not necessarily always right. Active citizens in this sense do not govern at every level; rather, citizens participate frequently enough when 'basic policies are

being decided and significant power being deployed' (Barber, 1984: 151). In such a case civil society becomes a vehicle enabling citizens to actively engage in the public affairs of the state. In other words through a well-organised and mobilised civil society, citizens are able to access the political realm and share with the ruling elite the terrain of policy formulation and decision-making. It is the power with which citizens have been endowed – power understood in this sense of political activity – that produces an interest in key political issues of which they must appropriate together with the ruling elite.

6. A Popular-Democratic Perspective in the Post-apartheid Context: A Case Analysis

So far in this chapter the term civil society has been discussed at a theoretical level. The purpose of this discussion was to advance the argument for a popular-democratic perspective of civil society while highlighting the shortcomings of a neo-liberal understanding of the term. The theoretical argument that has been presented in this chapter will be resumed in the remaining chapters of this study. As will be discussed in more detail, the case of the confrontation between the TAC and the South African government (regarding the provision of HIV medication at public health facilities across the country) has been selected as a means to illustrate this argument more effectively. The rationale for selecting a case study analysis is outlined in Chapter 2, with a summary of the selection and use of research methods being provided as well. As a result, a review of this study's methodology will be undertaken before returning to an analysis of the case in Chapters 3 and 4.

Chapter 2: Research Methodology

1. Research Statement

By using the case of the TAC's 'success' in pressuring the South African government to reform its controversial HIV/AIDS policy, this study will advance the argument for a popular-democratic perspective of civil society.

2. Research Design

2.1. Methodology

Because of the field of enquiry, the methodology of this study can be classified as qualitative. This research design employs an empirical approach in which both primary and secondary data sources are used. In this study the interview is used as a primary source of data, while newspaper articles, TAC and South African government documents, and other published material constitute the secondary sources.

2.2. Selection of the Case

In an attempt to shed light on the relations between the state and civil society in the post-apartheid context, this study will undertake a case analysis of the confrontation between the South African government and the TAC.[16] As an AIDS activist movement and organisation of civil society, there are a number of reasons why the TAC has been selected as a unit of analysis. The most significant reason is that the TAC has – arguably – been the most active and influential social actor to confront the government regarding its position on HIV/AIDS. Also, on numerous, if not all, occasions the TAC has been at the forefront of civil efforts to bring affordable and even free ARV medication to all South Africans living with HIV/AIDS. While the importance of the TAC should not be overlooked, it is necessary from a methodological point of departure to note that this study does not present a descriptive analysis of the organisation itself (for example, an

[16] It is not possible in the selected case of this study to refer to the confrontation between the state and civil society. This would suggest that various institutions of the state in South Africa were in agreement as to an appropriate HIV/AIDS policy, which was not the case. As discussed at a later stage, the executive arm of the state, the government, was strongly opposed by the juridical arm of the state, as exemplified in the High (2001) and Constitutional (2002) court judgments of the government's HIV/AIDS policy. The TAC, in part, used the juridical apparatus of the state to successfully compel the executive to reform its HIV/AIDS policy. The case of the TAC-government confrontation also reiterates the point that the government is not equivalent to the state, as the government for the most part was in continual contradiction with the dominant state biomedical perspective of HIV/AIDS.

account of its inner managerial practices, funding sources, budgetary allocation, elective processes, racial/class composition, and so on). Rather, as a unit of analysis, the TAC is selected in order to produce an understanding of something else.[17] In this respect, the confrontation between the government and the TAC will be used to underline the shortcomings of a neo-liberal perspective in its understanding of civil society. It is at this juncture that the argument for a popular-democratic perspective of civil society will be presented throughout the course of this study.

3. Data Collection

3.1. Interview

Structure of the Interview. In this study, the interview, as an instrument of research, is considered to be the source of primary data. The interview, generally speaking, is 'a special type of conversational interaction… designed for the purpose of improving knowledge' (Wengraf, 2001: 3). In this study, two types of conversational interaction were used: an elite and a semi-structured interview. An elite interview pertains to interviewing someone in a position of authority that is 'capable of giving answers with insight' and possessing a comprehensive grasp of what is being researched (Gillham, 2000). The interviews used in this study were also semi-structured in format. A semi-structured interview lies on the continuum between the structured and the unstructured interview, where questions are not pre-determined with a limited response category as in the structured interview nor are they as flexible and open as in the unstructured interview (Fontana & Frey, 2000).

In this study, interview questions were orientated around three particular themes. Questions emerging from the first theme were related to the concepts of 'civil society' and 'democracy'. More importantly, these questions were formulated to capture the extent to which the TAC enabled citizens to actively partake in the day-to-day issues of HIV/AIDS. Thus questions related to the first theme were posed in the following ways: 'Why can the TAC's 'success' be considered democratic?', 'How can the TAC continue

[17] Stake (2000: 437) refers to this type of analysis as an instrumental case study: where a particular case is selected primarily in order to produce an understanding of 'something else' or conducted for the sake of some 'external interest'.

to enable the participation of citizens in key public health issues?' and 'Will citizens (as a result of the TAC's success) become isolated from influencing and shaping HIV/AIDS policy in South Africa?'

Questions structured according to the second theme aimed to ascertain the TAC's position with regards to the HIV/AIDS debate in South Africa. Closely related to this theme is the discursive position held by the TAC. Questions such as 'Why has the TAC been so critical of President Mbeki?', 'Does the TAC acknowledge the role of socio-economic factors in the increasing HIV infection rate?', 'What does the TAC make of the claim that a substantial number of South Africans support Mbeki's views?' were relevant to this theme.

From the third theme, questions were posed in order to gain an understanding of the TAC's relation to the scientific and medical community. Thus, questions were framed as follows: 'What is the relationship between the TAC and science?', 'To what extent has the TAC used science in its campaign against government?', 'Is the TAC the mouthpiece for the scientific and medical community?' and 'To what extent does the TAC's emphasis on science limit the participation of citizens in HIV/AIDS issues?' Questions relating to these three themes were asked in all of the interviews. Where necessary, questions probing issues related to these themes were further posed.

Selection of the Research Participants. For the interviews, research participants were selected according to their role and position within the TAC. Given the methodological design of an elite interview it was decided that members of the TAC leadership, and not rank and file, would be available for participation. Leadership members were thus selected according to the position held in the National office, the National Executive Committee (NEC) or the provincial and local offices of the organisation. Because the interview questions required an adequate understanding of a number of complex concepts such as 'civil society', 'democracy', 'science' and 'ideology', it was decided that TAC members who were also academics (working in a tertiary educational institution) would also be eligible for participation. It should be noted here that the selected participants for this study were not representative or constitutive of the TAC itself. Rather, participants were selected on the basis that they were the TAC's public spokespersons in the HIV/AIDS debate.

The following is a list of TAC members interviewed with their positions and roles in the organisation:

- Zachie Achmat – Chairperson and founder of the TAC.
- Annie Devenish –Researcher at the University of Durban and former local TAC branch co-ordinator.
- Mandisa Mbali – TAC member and researcher of the University of Durban.
- Sifiso Nkala – Organiser of the KwaZulu-Natal provincial branch.
- Cindy – Provincial co-ordinator of the KwaZulu-Natal TAC provincial branch.
- Zolani Mente – Member and treatment practitioner of the Gauteng TAC local branch.
- Charlotte Zitha – Chairperson of the Kwateme local branch, Gauteng.
- Xolani Kunene – Provincial organiser of the Gauteng branch.

Procedure of Interviews. Interviews were scheduled and conducted according to the following process. Participants were contacted either by telephone or by email. A cursory outline of the study's subject matter was provided to participants, who were then requested to partake in an interview. Those who agreed to participate consequently gave their consent to be interviewed. On the day of the interview, participants were briefed about their ethical right to confidentiality and anonymity. Participants were then informed that their responses would be recorded – none of the participants objected to being recorded. Furthermore, after having been asked, no participants wished to remain anonymous or offer information in confidentiality. Interviews often lasted the duration of 20-40 minutes. Following the interviews, the recorded conversations were transcribed into both electronic and paper format.

3.2. Newspaper Articles

In this study, newspaper articles were used as a secondary source of data collection. These articles were accessed electronically from a database housing the majority of South Africa's newspaper collections. Newspaper articles were used as data in two ways. First, as an invaluable source of information, newspaper articles capture and disseminate

relevant and important details not necessarily found in journal articles or other published material. Newspaper articles also publish important comments, opinions, remarks and statements given by role players as important historical events unfold. In this respect newspaper articles were used to reconstruct a history of TAC-government relations as well as to provide a rich source of viewpoints gathered from members within the TAC and government politicians. Second, newspaper articles were also used to reflect the discursive character of the HIV/AIDS debate in South Africa. In this debate, the media (the print media in particular) were uncritically supportive of the TAC (and the dominant discourse of HIV/AIDS) and highly critical of the South African government. As part of civil society, the media played an important role in generating public resistance towards the latter's HIV/AIDS policy. It is in this respect that the partiality of the media's reporting directly contributed to the shaping of the parameters of the HIV/AIDS discourse in South Africa.

3.3. Published Material

Despite the public attention generated by the TAC, little has appeared in the way of an in-depth analysis (covering the length of a book, for example) of the organisation. Though the events surrounding the TAC's campaign against the government were recorded and documented frequently in the media, academic interest in the TAC has only recently begun to appear. Nevertheless, a number of published texts on the TAC, mostly journal articles, have been available and have thus been used in the course of this research.

3.4. Law Reports and Transcriptions

In the preliminary period of this research, law reports and transcriptions of the judge's rulings were frequently used as sources of data. Since the TAC's initial 'successes' came via the legal system, these sources were of importance in that they expounded on the judiciary's reasons for ruling in favour of the TAC and not the South African government. Law reports and transcriptions were further useful in that they documented the legal arguments made by the South African government and the TAC with regards to

the implementation of an ARV rollout program. Reports and transcriptions were attained by accessing electronic databases located at the University of Pretoria's Law faculty.

3.5. South African Government and TAC Documents

As sources of data, South African government policies and documents, and TAC documents and manifestos were particularly valuable. The government's HIV/AIDS policies and documents were accessed electronically via its official online site (www.gov.za). These documents and policies were analysed in order to attain a clearer understanding of the reasons and thinking behind the government's position on HIV/AIDS. TAC documents and manifestos outlined a number of useful insights into the organisation, for example, its treatment and literacy campaigns and organisational structure. The online site (www.tac.org) where a substantial amount of information was retrieved also provided a range of commentaries, quotes and viewpoints communicated by key TAC members that would not have been found elsewhere in published material.

4. Discussion of the Research Process

4.1. Approaching prospective participants

As discussed above, primary and secondary data was collected through interviews, published material, TAC/Government documents, law reports and newspaper articles. In South Africa, a good deal of information and discussion of the TAC has appeared in journal articles and in the mass media. This is often because the media has sought to sensationalise the TAC's campaigns while the academic community has looked to the organisation to reframe the state-civil society debate. Given the degree of public attention devoted to the organisation, it was at first assumed that prospective TAC participants would be difficult to approach. Contrary to these initial assumptions, the latter displayed an open and willing consent to be interviewed. As a matter of fact, Zachie Achmat, the TAC chairmen, commented that his organisation looked forward to being interviewed by South African students, as the TAC had been inundated with interview requests from international researchers. Overall, it was thus found that leading members of the TAC were accessible and open to participating in research interviews.

4.2. Discussion of Interviews

Before proceeding with the interviews, a concern arose as whether the research interviews would be of an overly intellectual nature. For example, participants were asked to discuss their organisation (TAC) in the context of a number of concepts ranging from 'civil society', 'democracy', 'science', 'ideology' and 'socio-economic rights'. In this respect an issue of reliability was raised with regard to interview questions. In order to overcome this potential methodological problem, participants were asked a number of preliminary questions in an attempt to determine their understanding of a range of concepts and issues. For example, participants were asked 'Is the TAC a social movement or civil society organisation?', or 'Some people say that the TAC is a 'success', why is this so?' Depending on the initial responses of participants, further questions, varying in degree of complexity, were posed. At this point, any intellectual or technical questions were reformulated and thus simplified by removing academic jargon. For example, the questions 'How can the TAC be said to substantiate the idea of democracy in South Africa?' and 'What is the ideological position of the TAC on science?' were rewritten to read 'Why is the TAC a good thing for democracy in South Africa?' and 'What is the TAC's position on science?' It should be pointed out, nevertheless, that participants were adequately, and for the most part, well informed about a number of issues regarding the political, social and economic aspects of the TAC's campaign. This can be attributed to a large extent to the organisation's literary campaign which has sought to educate its staff and members as well as the broader public about various issues regarding HIV/AIDS (see Chapter 3 for a discussion on this point). In this respect it was found that participants were equipped intellectually with the capacity to answer certain technical questions albeit by way of their own interpretation and understanding.

It should be further noted that interview questions did not seek to capture theoretically accurate or objective responses. In this respect, the methodological issue of validity did not determine the interpretation of participant responses. Rather, as a methodological point of departure, this study acknowledged the 'embeddedness' of participants in their respective social contexts. Responses were therefore valued in terms of each participant's

interpretation and understanding of the TAC's 'success'. As an illustration of this point, the question 'Why is the TAC a good thing for democracy in South Africa?' did not seek to determine whether the organisation's campaign was inherently 'good' or 'bad'. Rather, this question sought to understand how participants came to perceive their organisation as substantiating the condition of democracy in this country. Interview questions also sought to capture the awareness of participants in terms of the organisation's impact on the various political, social and economic spheres of South Africa. Participants were questioned about difficult topics such as the TAC's ideological position, the organisation's relation to science, Mbeki's views on HIV/AIDS, socio-economic issues, and so on.

For the most part, participants were unanimous in their responses to the majority of questions. Participants sought to downplay the suggestion that the TAC's reliance on science was an ideological position; science was considered to be a value-neutral instrument supporting the organisation's treatment and literacy campaigns. Thus the questions 'Does the TAC see itself as a voice-piece of the scientific and medical community?' and 'Is the TAC an ideological defence of HIV/AIDS science?' were often answered in a manner that situated the organisation independently of science. For the most part, participants described both the response of Mbeki and the South African government to the HIV/AIDS crisis as a lack of political will, indicating therefore that the TAC was left with no other alternative than to pressure the latter to make ARV medication available at public health facilities countrywide.

5. Summary of the Argument

The responses provided by the participants (as described above) are informed by a particular understanding of civil society. These responses are also consistent with the interpretations given by the media and academia of the TAC's 'success' in pressuring the government to reform its position on HIV/AIDS. By in large, the popular understanding of the confrontation between the government and the TAC has been framed within a neo-liberal perspective of civil society. As mentioned in the 'Introduction' of this study, the case of the TAC-government confrontation has, for the most part, been interpreted by commentators in the media and academia in a manner that is at odds with a popular-

democratic perspective of civil society. As a result, the TAC's 'success' has been understood in terms of the organisation's capacity to confront the government in the name of a rights-based approach. Implicit in this neo-liberal interpretation is the idea that the TAC has fulfilled its role as a 'watchdog' or 'counterweight' to the government's controversial position on HIV treatment. While this reading is partly accurate it is not sufficient in itself to account for the idea of civil society as a realm enabling an active citizenship. Nor can this interpretation purport to provide a more comprehensive and critical analysis of the TAC's 'success'. This is not to suggest that a neo-liberal perspective is incapable of interpreting the 'success' of the organisation. It is accepted that such a perspective is capable of taking into account the potential for political action, as in the case where citizens mobilise to counter state intrusion, or when citizens organize to protest unpopular government policy, or even when citizens periodically arrive to cast their ballots. But when such opportunities for political mobilisation and organisation elapse it is expected that citizens return to the realm of civil society as passive subjects. In this sense the idea of an active citizenship is confined to an engagement or disengagement of civil society from the state. It is this neo-liberal formulation of state-civil society relations that is contested both in theory and in the interpretation of the TAC's 'success'.

Chapter 3: The TAC and AIDS Activism

1. Introduction

From a popular-democratic perspective the case of the TAC-government confrontation is used to show how an organisation of civil society enabled citizens to directly affect an important public issue. Here, citizens belonging to and supporting the TAC mobilised to influence a health care issue that would have had a significant impact upon their lives. In this chapter it is therefore discussed how the TAC illustrates a popular-democratic meaning of civil society. The discussion documents the strategies utilised by the TAC in pressuring the government's to reform its controversial position, as well as the initiatives employed by the organisation to enable citizens to participate in the day-to-day management and treatment of the HIV/AIDS epidemic.

2. The Politics of AIDS activism

In South Africa, where the importance and influence of civil society was thought to have progressively diminished since the transition to democracy (Johnson, 2002; Neocosmos, 1999, 1996; Kotze, 1998), the emergence of the TAC is an interesting case. For, in many respects, it can be said that the organisation has successfully reinvigorating the kind of political activism that was witnessed in the mass mobilisation of organisations and movements of the liberation struggle against the apartheid state. But while it is quite correct to link the TAC's activism to the more generic liberation-style activism of the 1980s, it can be stated that the specific nature of the organisation's tactics were first witnessed during the AIDS movement in the United States, where the HI virus was reported to have appeared in the medical literature towards the close of the 1970s (Altman, 1986).

In the United States, HIV/AIDS was first thought to be a gay disease – called by the acronym GRID (Gay Related Immune Deficiency) – because most of the earliest reported cases were contained within that population group (increasing cases of the disease would also appear in three other groups at the time: intravenous drug users, haemophiliacs and

Haitians).[18] Without substantial or adequate knowledge regarding the general nature of the disease, the initial onset of HIV/AIDS became highly politicised as misinformation, speculation and stigmatisation first entered the public arena in 1983.[19] Stigmatised not only as 'queers' but also as 'plague ridden pansies', gays were subsequently subjected to a double backlash from conservative factions claiming that AIDS was a divine intervention cleansing the American society of its impure elements (cited in Erni, 1994: 52). While the political issues surrounding the disease intensified, little was done on a ground level to develop effective treatment responses. In light of these concerns it became apparent that the gay community was facing an additional problem as harrowing as the forces of stigmatisation: an apathetic establishment in which neither the government nor the medical community showed any signs of urgency in dealing with the epidemic.[20]

> [What] was so startling at the beginning of the epidemic was that the entire concept of medical expertise was momentarily stood on its head, as the communities most affected by the syndrome rapidly developed an extraordinarily wide range of survival skills while the customary 'experts' stalled. It was quite clear that this was a problem which could not be satisfactorily dealt with within existing structures. It was equally clear that the political will to recognise the existence of the problem, let alone deal with it, was not there. Rendered smug and uncaring by deeply engrained homophobia, the establishment was dragging its heals while the death toll mounted (Wilson, 1992: 103).

[18] Gay activists did much to contest this discriminatory labeling of the disease; in 1982 GRID was subsequently renamed to read AIDS.
[19] It is also in this year that both French and American scientists isolated the HI virus, which was originally named LAV (lymphadenopathy-associated virus) and HTLV-III (human T-cell leukaemia virus) respectively.
[20] Considering that AIDS was first thought to have been reported in the late 1970s, the Reagan administration made its first public statement on AIDS in 1987 shortly after the FDA's (Food and Drug Administration) approval of AZT, the only approved anti-HIV drug in the United States by 1990 (Erni, 1994).

Realising that someone would have to take the initiative, an American activist Larry Kramer incited the gay community to take action and press the biomedical establishment to hasten the development of new AIDS treatments (Wachter, 1996). Inspired by Kramer's 'call to arms', the gay community and individuals living with the disease subsequently mobilised and the AIDS activist movement, as a result, began in earnest in 1987. According to Bastos (1999) the period from 1987 was one of three periods in which AIDS activism in the United States could be bracketed. Whereas from 1982, marking the start of the first period, AIDS activism was concerned with fund raising, establishing networks amongst gay communities and volunteer recruitment, the second period saw a more confrontational yet articulated PWA (persons living with AIDS) movement. This period of political activism would also see the emergence of one of the most prominent AIDS movements called the AIDS Coalition to Unleash Power, otherwise known as ACT UP. Encapsulated by one of their most visible and recognisable slogans, 'Silence=Death', ACT UP, in principle with the emerging consensus in the gay community at the time, endeavoured to radically challenge the mainstream and dominant representations of HIV/AIDS. The third period of activism emerged in the early 1990s and effectively saw the fragmentation of the AIDS movement into distinct groups, some choosing to specialise in drug research (for example, the Treatment Action Group (TAG)), others retaining the radical activism exemplified by ACT UP, while others chose to pursue the role of service providers to people living with AIDS (Bastos, 1999).

In these three historical periods AIDS activists in the United States sought by various means to actively involve themselves in the broad spectrum of issues related to the epidemic. The most well-known and effective of these forms of participation were witnessed in 1) the guerrilla-style and theatrical-type activism displayed by organisations like ACT UP (Crimp, 1988a), 2) the self-education of PWAs in AIDS issues (Epstein, 1996), and 3) the institutional collaboration of activists with the medical establishment in the development of effective treatment responses for HIV/AIDS (Bastos, 1999).

1) At the time of its emergence, the AIDS activist movement was a direct derivative of the new social movements that had originated in the 1960s and 1970s. Like the latter, the former comprised a heterogeneous collection of social actors, grassroots activists, journalists, academics, health educators, medical experts and advocacy organisations. As

its central objective, the AIDS activist movement in the United States campaigned to disrupt the silence and complacency that initially surrounded the disease in the early 1980s. Because of the sluggish response by the medical community and the United States government, activists sought to bring the full impact of AIDS by whatever civil means necessary to the attention of the public arena. Here, activists took to the streets in a manner reminiscent to that of the anti-apartheid movements in South Africa, which demonstrated the very tactics that ACT UP was to copy in its confrontation with the AIDS establishment (Sawyer, 2002). Drawing equally from the experience of anti-war and civil rights movements, AIDS activists realised that peaceful civil disobedience campaigns risking arrest were likely to garner both the attention of the public and the media. As a result, activists resorted to outlandish street theatrics in an attempt to bring across novel and striking AIDS messages to the public, which in most cased led to televised or media reported arrests. In this respect, public demonstrations, marches, protests, sit-ins, takeovers, funeral enactments, media propaganda and so on, were all tactics that challenged the dominant and silent (mis)representations of AIDS. Importantly, the AIDS activist movement also provided an outlet for 'an otherwise horrendous situation… sometimes it was through humour, style and camp; sometimes it was through direct action' (Shepard, 2002: 13).

2) In addition to the street activism witnessed in the 1980s, an undergoing process of 'expertification' – where activists literally became experts in viral aetiology – also marked out a defining feature of the AIDS movement (Epstein, 1996: 13). 'Expertification' was an attempt to challenge the dominant representations of AIDS being produced by both the AIDS establishment and the general public. As Epstein (1996: 8) notes:

> Perhaps the most striking feature on the landscape of AIDS politics is the development of an 'AIDS movement' that is more than just a 'disease constituency' pressuring the government for more funding, but it is in fact an alternative basis of expertise. The members of this movement are not the first laypeople to put forward claims to speak credibly on biomedical matters. But this is indeed the first social movement in the United States to accomplish the large scale conversion of disease

> ‘victims’ into activist experts. In this sense, the AIDS movement stands alone, even as it begins to serve as a model for others.

This undertaking in self-education sought to dissolve the expert-layman and doctor-patient binary, a division which rendered persons living with AIDS as both the objects and subjects of scientific and medical practice. By informing themselves about relevant issues, activists attempted to wrest control of their own bodies and play a role in the production of HIV/AIDS knowledge. As a result, knowledge no longer became the monopoly of mainstream science. As activists became informed about HIV/AIDS issues, a sense of empowerment and control began to emerge within the movement, a sort of optimism that was based on the assumption that through knowledge a cure for AIDS would eventually be discovered. Inspired by the conviction that one could proactively play a role in the management of the disease, activists took the initiative to assess and explore the viability of alternative medicines, develop holistic approaches to the disease, develop education programmes, disseminate information, perform self-administrated drug treatment, and question the efficacy and toxicity of pharmaceutical drugs such as Azidothymidine (AZT) (Callen, 1988; Crimp, 1988b; Sawyer, 2002). Thus the popular lexicon ‘Knowledge = Cure’ became the flipside of the foreboding ‘Ignorance = Death’ slogan of AIDS activist organisations such as ACT UP (Erni, 1994: 64). Self-education thus became an articulated as well as an intellectual feature of a movement that forced the general public, government officials, scientists, and prominent bureaucrats in the medical industry to acknowledge, recognise and include activists in the decision-making process of HIV/AIDS.

3) The expertise of many self-educated activists and their ability to leave an impression on important players in the AIDS establishment resulted in their inclusion and participation in the research panels and boardrooms of governmental agencies and pharmaceutical companies. Prior to their acceptance by the AIDS establishment, activists had to struggle to access the institutional arrangements of HIV research. At first, activists collaborated with primary-care physicians to pioneer new forms of knowledge about HIV/AIDS. This relationship led to the establishment of community based trials which sought to test a variety of treatment options without being encumbered by administrative

delay and bureaucratisation. Community involvement in treatment research effectively removed the power of scientists, who were in command of the laboratory and the methodological processes attached to it, while overcoming the slow progress of the medical establishment towards advancing a cure for HIV/AIDS. As Epstein (1996: 216) points out, the advent of community-based research thus 'promised to bring scientific knowledge-production closer to popular control.' Nevertheless, the subsequent 'expertification' of AIDS experts and the 'cumulative' advances in the science of HIV/AIDS treatment eventually led to a decline in the confrontational and visible activism of the 1980s. This shift (from revolutionary to normal science) was further hastened by the spread of HIV/AIDS to other population groups, namely heterosexuals, women and popular icons (Rock Hudson, Freddy Mercury and Arthur Ashe, for example) not only in the United States but in other countries as well. In the 1990s, TAG, an offshoot of ACT UP, shifted the focus from treatment activism to the monitoring of sophisticated AIDS research. Specialising in the language of science, TAG pushed for new avenues of AIDS research, advocated longer periods of investigation of newly released drugs, and pressed for the development of a new line of drugs called ARVs (Bastos, 1999).

3. Introducing the TAC

In many respects, the TAC embodies many of the characteristics that were particular to the AIDS activist movement throughout its history in the United States. The TAC is 'a voluntary, non-profit association of organisations and individuals' that has campaigned for the provision of free and affordable HIV/AIDS treatment at public health facilities throughout South Africa (TAC, 2003a: 3). The organisation was formed in 1998, from a group of 15 protesters demanding access to 'life saving' medication designed to fight the HI virus (TAC, 2003a: 7). While, according to the TAC, such medication was freely available in Western countries, many South Africans were not yet aware of the possibility that HIV/AIDS could be treated. This medication was also expensive and thus beyond the reach of the majority of South Africans living with HIV/AIDS. As a result, TAC founder and current chairperson, Zachie Achmat, decided to launch a campaign informing people of their constitutional right to affordable health care – specifically their entitlement to

ARV medication. It is the commitment to this treatment agenda that has seen the TAC evolve into the most prominent and recognised civil society organisation in this country today.

The TAC's central aims and objectives include amongst others the 'campaign for affordable treatment for all people with HIV/AIDS'; to 'fight for treatment for pregnant women with HIV to reduce the number of children who contract the virus'; to 'campaign for a health system that provides equal treatment to all South Africans'; and to teach 'others about HIV/AIDS treatment' (TAC, 2003a: 3). Since 1998 the TAC has campaigned to bring about these objectives by various means, despite relative degrees of resistance from both the pharmaceutical industry and the South African government. The organisation has, for example, launched its own treatment literacy campaign, set up workshops informing people of the science of HIV/AIDS, and even defied patent laws to import cheaper generic ARVs from countries such as Thailand and Brazil. However, it was the highly successful campaign against the pharmaceutical industry and the prolonged struggle with government that established the TAC as the leading advocate of free and affordable ARV medication for people living with HIV/AIDS in this country.

The TAC's first prominent campaign, which earmarked the organisation as a notable and capable AIDS activist group, was launched in 1999 to contest the decision of the United States government to place South Africa on a watch list of countries to face possible economic sanctions. The United States attempted to prevent the South African government from reducing the prices of essential medicines through the Medicines and Related Substances Control Act of 1997 – a policy which made it possible for patented drugs to be produced locally, allowing for the importation of cheaper patented drugs from other countries, and principally giving permission for the importation and production of cheaper generic drugs – drew protest from the TAC and a number of international AIDS activist organisations. Along with the United States, national and international pharmaceutical companies aligned to oppose the Medicines Act, claiming that it contravened a number of South Africa's patents law and undermined the 'ability of the pharmaceutical companies to charge different prices in different parts of the world', an implication that could threaten profits needed for further HIV/AIDS research (Baleta, 2001: 775).

In 1999 the pharmaceutical industry, represented by the Pharmaceutical Manufacturer's Association (PMA), moved to bring legal action against the South African government, consequently generating immense public interest in the case and provoking the TAC to react in protest. In September that year the organisation demonstrated outside the offices of the PMA with the demand that the lawsuit opposing the legislation of the Medicines Act be dropped. Further TAC demonstrations took place in the months of November and December and continued into the following year of 2000. In early 2000 the TAC returned with impetus to take up its campaign against the PMA. The organisation led more than 1500 people to parliament demanding government to begin the production of generic ARVs in defiance of the PMA's pending lawsuit. Later that year, in October 2000, the TAC took matters into its own hands by illegally importing (from Thailand) fluconazole, a drug used to treat AIDS related infections. In a symbolic act of defiance the organisation then proceeded to distribute the drug freely to those in need of it (*Business Day*, 18 October 2000; *City Press*, 22 October 2000). Two months later the Medicines Control Council (MCC) granted the TAC permission to import the generic version of the drug from Thailand – despite the fact that the pharmaceutical company Pfizer held a patent right on the drug (*Business Day*, 1 December 2000).

On March 5, 2001, the South African government and the TAC faced the PMA in a court case that had created a considerable amount of public attention. Prior to the case the TAC had called for 'a global day of action against pharmaceutical company profiteering' and had managed to receive support from numerous international AIDS activist organisations in Australia, Brazil, Britain, Canada, Denmark, France, Germany and the United States (TAC, 2003a: 13). Amidst increasing negative publicity generated by public demonstrations and protests, the United States government was forced to retreat from its position while the PMA withdrew its lawsuit on April 19, 2001. Placing the PMA's decision into context, the TAC remarked:

> One of the best ways to measure the TAC's success is to look at the way the pharmaceutical industry has responded. When we were established drug companies insisted that they were already charging the lowest possible prices for their products

> in developing countries [sic]. Two years later the growing international outrage over the lack of access to drugs has sent the industry into panic. Suddenly new and larger discounts are being announced weekly. […] This is a positive step and a direct result of public pressure, although prices are still too high for developing countries' budgets. The discounts show how much profit drug companies are making on life-saving medicines and the TAC will keep fighting them to force them to reveal what these medicines actually cost to manufacture (TAC, 2003a: 5).

In withdrawing litigation against the South African government, the PMA essentially acceded to the demands of an organised civil society campaigning for affordable health care. The PMA case thus marked a significant turning point in the politics of HIV/AIDS in South Africa. Not only did the case bring the TAC into the public limelight but it also exemplified the potential and influential role civil society could play in a public health issue. Following the success in pressuring the pharmaceutical industry to lower the costs of ARV medication, the TAC turned to the South African government to ensure that these drugs could be accessed at public health facilities across the country. For both ideological and logistical reasons the South African government had yet to implement a program making such medication available. Instead, the government had set up 18 sites throughout the country for the purposes of determining the operational issues surrounding the distributing of ARV medication. Some of these issues would include, for example, the close inspection of the efficacy as well as the short and long term effects of Nevirapine, the costs involved in distributing the drug at public health facilities, and the capacity of the public health system to ensure this distribution (South African Government, 2002a).

In response, the TAC accused the government of transgressing the constitutional right of citizens to affordable health care, since the majority of South Africans living with HIV/AIDS could not access these pilot sites. As reviewed in more detail below, the organisation consequently embarked upon a series of civil disobedience campaigns, augmented by legal action, in an attempt to pressure the government to implement a more comprehensive ARV treatment program. The first signs of the TAC's efforts in pushing for policy reform appeared when the government, on April 17, 2002, announced that it would alter its position on ARV treatment. Admitting that public pressure had played an

enormous influence in leading to such a decision, Mbeki acknowledged that the government's HIV/AIDS policy was becoming a major issue that undermined South Africa's interests (*Sunday Independent*, 21 May 2002). As a result, the government amended its policy on AIDS to include a national mother-to-child-transmission (MTCT) prevention program, planned for implementation in 2003, while considering a 'comprehensive package of care for survivors of sexual assault, including counselling, testing for HIV, pregnancy and STIs [sexually transmitted diseases]' (South African Government, 2002b).

Despite these 'short-term' changes to its HIV/AIDS policy, the government continued to argue that more time and work was needed to establish the 'long-term impact and administration of Nevirapine' (South African Government, 2002b). Some of these issues included the already stated problems of ARV resistance, possibilities of relapse, and the possible negative consequences of the drug for both mother and baby. The government in conclusion cautioned that it would take more than a year to determine whether it would be advisable to make Nevirapine accessible at public health facilities (*ANC Today*, 2002). As the TAC prepared for further civil disobedience campaigns and litigation, the South African government on August 8, 2003, announced that it would develop and implement an ARV rollout program for the public sector in the beginning of the year 2004 (South African Government, 2003a).

The August 2003 announcement indicated a substantial distancing of the government from its controversial HIV/AIDS treatment policy. This announcement was seen by the media and academia as a victory for civil society and democracy (in post-apartheid South Africa) in that a key policy decision could be influenced and shaped by the public sphere. More specifically, it can be said that this policy reform came about primarily through pressure exerted by civil society, particularly the TAC. In what respect is this understanding of the TAC's 'success' significant? Below an analysis will be presented in an attempt to address this question. Here, three initiatives of the TAC's campaign will be discussed for the purposes of illustrating the popular-democratic significance of the organisation's 'success' in pressuring the government to reform its controversial HIV/AIDS treatment policy.

4. The TAC and Non-Institutional Political Participation

In this study it is argued that an essential component of the TAC's 'success' has been its ability to enable the participation of citizens in an important public health issue. The organisation has managed to achieve this through the use of civil disobedience campaigns, marches, demonstrations and other public forms of protest – reinvigorating, as a result, a similar type of popular-democratic politics that was previously witnessed in the anti-apartheid movement of the 1980s. Though much of the public attention has been placed on the TAC, it would be incorrect to claim that the organisation has acted as a 'lone-campaigner'. The TAC has received assistance from various factions of society in South Africa including amongst others the Children's Rights Centre, the AIDS Consortium, the South African NGO coalition (SANGOCO), the AIDS Law Project and health practitioners; while other international organisations such as the Australian Foundation of AIDS, ACT-UP, the European Coalition of Positive People, Health Gap Coalition, Oxfam and Doctors without Borders (Medicins sans Frontieres) have rallied in support of the TAC.

The TAC's closest ally, apart from the media, has been South Africa's most prominent trade union federation, the Congress of South African Trade Unions (COSATU). The organisation has often relied on COSATU for the mobilisation of public support while the latter has seen 'participation in TAC as a way to ensure its members and the poor have access to proper health care services and treatment' (Vlok, 2000: 33; Mothapo, 2004).[21] Along with SANGOCO and the Federation of Unions of South Africa (FEDUSA), the TAC's ability to mobilise thousands of people has thus depended very heavily on the close support of other influential civil society organisations (Heywood, 2001). As Mbali (interview, 21 March 2004) points out, the single-issue campaign of the TAC has been its strength since opposition towards government's HIV/AIDS policy has come from a 'multi-sectoral civil society' that has been united in the need for accessible and affordable HIV/AIDS treatment.

Since its inception, the TAC has shown a willingness to employ non-violent protest initiatives by literally taken its campaign to the streets in an attempt to pressure both the

[21] Such has been the co-operation between the two that Mbeki once accused the TAC of infiltrating the trade unions (*Cape Times*, 2 October 2000; *Sowetan*, 24 January 2003; *Mail & Guardian*, 20 February 2003).

pharmaceutical industry and the government to make ARV medication affordable and accessible to South Africans living with HIV/AIDS. Though active since 1998, the intensity of the TAC's treatment campaigns only came into the foreground following Mbeki's public questioning of the science of HIV/AIDS and ARV treatment. Throughout 2000, the TAC conducted a series of campaigns in open opposition to the government's stance on HIV/AIDS. These campaigns included a number of civil disobedience initiatives ranging from fasting, negotiating, petitioning, marching, picketing, praying, sit-ins and rallying (*Sunday World*, 9 June 2000; *Citizen*, 17 October 2000; *Pretoria News*, 17 October 2000; *Cape Times*, 22 August 2001). In the latter half of 2001 and throughout 2002, the TAC intensified its campaigns in protest of the government's decision to limit the accessibility of ARV medication to a limited number of pilot sites across the country (*Cape Argus*, 8 October 2001; *Sowetan*, 19 July 2002; *Star*, 7 November 2002). In this period, civil disobedience campaigns were used to pressure the South African government into implementing the 2001 High court ruling (*Mail & Guardian*, 27 March 2003; *Cape Times*, 5 February 2003; *Sowetan*, 24 January 2003). In March 2003, the TAC launched its most intensive civil disobedience campaign in response to the government's refusal (along with corporate business representatives) to sign a National Economic Development and Labour Council (NEDLAC) plan (jointly drawn up by the TAC and COSATU) (TAC, 2004a). The NEDLAC plan committed the government to implementing a national strategy that would extend the access of ARV medication to adults and children with HIV/AIDS (NEDLAC, 2002). The subsequent refusal of the government to sign this document led the TAC and COSATU (with support from other civil society organisations) to launch one of the 'biggest protest demonstrations of post-apartheid South Africa' (*Star*, 17 February 2003; *Cape Times*, 5 February 2003). Because of the government's steadfast position on HIV/AIDS treatment, the TAC was thus placed in a position where civil disobedience initiatives were used as a 'last resort' (interview, Achmat, 7 July 2004). After the suspension of a week long civil disobedience campaign in March 2003, the TAC returned to civil disobedience initiatives later in July that year. As public pressure and opposition mounted, the government, recognising the rising difficulties its position was causing for itself prior to the national elections the following year, announced on the 8th of August 2003 that it would develop a

comprehensive treatment plan for the public sector by beginning of the following year (South African Government, 2003a).[22]

The shift in the government's HIV/AIDS policy was a significant event for AIDS activists, organisations and movements of civil society in South Africa. This event was also said to be an important step in the 'maturity' of this country's democracy. Though no direct parallels should be drawn between the liberation struggle and the TAC's defiance campaign, it is nevertheless important to point out that in both instances political participation was invigorated through popular organisation and mobilisation. In this respect, the TAC enabled a substantial number of citizens to express their position on an issue that would have a significant impact on their lives, in other words, the ability or the inability to access 'life saving' medicines. Since citizens could not influence government policy by institutional means – or such institutional participation via litigation did not prove to be effective – the TAC provided 'a platform for ordinary people to speak out' and potentially influence a given political decision (interview, Devenish, 22 April 2004). Here, the 'success' of the TAC in pressuring the government to reform its position on HIV/AIDS treatment showed that citizens could substantially shape and influence a key policy decision. It is essentially this potential capacity of civil society to enable citizens to influence government policy that is valuable from a popular-democratic perspective of civil society.

5. The TAC and Institutional Political Participation

As already mentioned, the influence of TAC is an interesting case because it confronted the South African government in a similar manner to that of the anti-apartheid movement in the 1980's. However, unlike the liberation struggle, the TAC has also confronted its adversary by using this country's legal system and the South African Constitution in a strategic manner. As a result, the organisation has been able to

[22] Reports appeared that members of the ANC's leadership were being confronted about the HIV/AIDS issue from a grassroots level during their preparation for the forthcoming elections. Another ANC insider was quoted as saying that the 'HIV/AIDS debate had been the ANC's worst public relations failure' and that that it was 'likely to cost the ruling party greatly in the elections unless something was done urgently to address it' *City Press* (10 August 2003).

compliment its use of both a popular and a contentious form of politics with a legal and socio-economic rights-based approach. The aim of the TAC's legal action has sought to bring the government's HIV/AIDS treatment policy under scrutiny, with the eventual goal of 1) legally enforcing the latter to provide Nevirapine, at public health facilities and 2) to oblige the state to set time frames for the implementation of a national MTCT prevention program (*Saturday Weekend Argus*, 16 September 2001; *Cape Times*, 22 August 2001; *Mail & Guardian*, 30 August 2001). In this respect, the TAC legally compelled the government to acknowledge the socio-economic right of citizens to affordable health services and medication (Jones, 2003; Klug, 2002; Schulze, 2002; Heywood, 2001; interview, Mbali, 21 April 2004; interview, Nkala, 22 April 2004; interview, Kunene, 30 June 2004). The TAC argued that the government had violated certain sections of the Constitution, amongst others, section 27(1): 'Everyone has the right to have access to health care services, including reproductive health care', and (2) 'The state must take reasonable legislative and other measures within its available resources, to achieve the progressive realisation of these rights'; and section 28(1)(d) 'Services must be provided impartially, fairly, equitably, and without bias (The Constitution of the Republic of South Africa, 1996). By appealing to the Constitution, the TAC therefore pressured the government to remain focused on the 'most vulnerable and disadvantaged' (Budlender, 2001: 131). It is often from this perspective that the TAC has understood its campaign to defend the ideals of democracy and 'good governance' in South Africa (interview, Nkala, 22 April 2004; interview, Mente, 25 June 2004; interview, Mbali, 21 April 2004).

In the context of this study, the TAC's use of the South African legal system and the Constitution is of importance for another reason. What should be noted here again is the manner in which the organisation has enabled citizens to participate in a key HIV/AIDS policy issue. In contrast to the non-institutional participation discussed above, the TAC has also enabled the active engagement of citizens in the institutionalised setting of the legal system. The use of the courts as a 'last resort' is significant here since the government showed no intentions of reversing its treatment policy at the time (TAC spokesman in the *Pretoria News*, 23 October 2001; Achmat in the *Cape Times*, 22 August 2001). By bringing the government's litigious policy into the public, as well as

into the legal realm, the TAC enabled the ideological and logistical issues surrounding HIV treatment to be contested, and subsequently arbitrated by the juridical arm of the state. Thus, when the High and Constitutional court judges ruled in favour of the TAC, a significant amendment to the governments HIV/AIDS treatment policy was ordered.[23] It is because of the eventual legal action brought by the TAC that such a policy amendment was made possible. By using the courts, the TAC was therefore able to shape and formulate a key policy decision. In effect, the organisation showed that policy decisions did not necessarily reside in the executive domain of the state (i.e. the government) and that citizens could mobilise to influence government policy through an institutional (juridical) arm of the state.

The TAC has also enabled the institutional participation of citizens in another way. The institutional character of the TAC is evident in its branch and community based structure, which has further facilitated the participation of citizens in addition to the non-institutional channel of protest and demonstration. According to Mbali (interview, 21 April 2004) the image of the TAC as a social movement led by a group of AIDS activists has in a sense shifted to take on the characteristics of a non-governmental organisation (NGO). This perspective is congruent with the development of the organisation as a group of protesters with no budget in 1998, and less than R200 000 in the first two years of operation, to an influential civil society organisation having spent more R15 million in 2004 and with over 40 full time paid staff members across the country (interview, Achmat, 7 July 2004). The TAC's branches can be said to fulfil a number of functions. The first, which will be discussed below, is concerned with treatment literacy and political education; the remaining functions are concerned with issues related to public awareness and mobilisation, local network building, health service support and monitoring, the development of support groups, political lobbying, and supporting social security campaigns (for example, the Basic Income Grant) (Mthathi, 2003).

One form of institutional participation by TAC members can be witnessed in the establishment of task teams for the purpose of monitoring the government's ARV rollout

[23] It is for this very reason that the government contested the High court's ruling, claiming that the order transgressed the necessary division of state powers by determining the nature of government policy (Hopkins, 2002b).

program (interview, Devenish, 22 April 2004; interview, Kunene, 30 June 2004). In these task teams, TAC members are able to influence and shape the decisions that are made with regards to issues such as the distribution and administration of HIV/AIDS medication. What is considered democratically appealing about the branch structure of the TAC is its 'down-to-top' approach (interview, Nkala, 22 April 2004). In this respect participation from below is strongly encouraged and facilitated through the institutional apparatus of the TAC. In branch meetings, members of the TAC, NGOs and individuals converge to discuss issues of importance with regard to HIV/AIDS epidemic. In this respect, the function of the organisation's leadership on a provincial level is to facilitate this process by doing the administrative work and giving guidelines for the points of discussion (interview, Nkala, 22 April 2004). The National Executive Committee (NEC), a body of 15 elected representatives elected by secret ballot by TAC members at the organisation's annual conference, decides on important issues that transcend local and provincial concerns. Some of the issues would include, for example, the decision to suspend and resume civil disobedience campaigns, to determine the obstacles and challenges to the government's ARV rollout program, and to decide the most appropriate responses to the government's progress (or lack thereof) in implementing an ARV rollout program (TAC, 2004a). The NEC is however accountable to the will of its membership, as in the case when the organisation's first civil disobedience campaign was suspended. After facing discord within its membership for taking this decision, the NEC put the issue to a majority vote at its National Conference in Durban. The result of that vote led to the TAC resuming its second round of civil disobedience in July 2003 (interview, Achmat, 7 July 2004; TAC, 2004a).

6. Enabling Citizen Participation though Education

One of the most important tasks of the TAC has involved the education of its members and the broader community about issues related to HIV/AIDS. From the context of this study, the organisation's literacy campaign has fulfilled a vital role by empowering citizens with the knowledge to make informed decisions as they confront the complexities of the disease. Treatment literacy is an important objective in the TAC's agenda, yet it is a task that has been devoted insufficient attention by the public,

particularly the media who have rather sought to focus on the controversial events surrounding government's refusal to provide ARV treatment (interview, Achmat, 7 July 2004). The TAC has suggested that its treatment literacy campaign is one of the most critical tools in bringing about an effective public health system as well as an effective HIV/AIDS treatment plan (Achmat, 2003). The strong literacy element that has recently appeared in the TAC suggests a move away from the primary focus on treatment access and affordability (since the pharmaceutical industry's decision to reduce the prices of ARV medication and government's move to finally implement a national rollout program). As a result, the TAC's objectives have been re-orientated to educating and informing people and communities about the basics of HIV/AIDS treatment. Some of these objectives have focused on a broad variety of topics ranging from MTCT prevention, ARV therapy, the treatment of opportunistic infections, post-exposure prophylaxis, safe sex, nutrition, basic income grants, the science of HIV and the patents commission (TAC, 2003b). The literacy campaign has also specifically targeted people who live with HIV/AIDS as well as doctors, nurses and health care workers about basic medicines and basic positive living. More broadly the TAC has also addressed issues surrounding the political economy of health, the law, the enforcement of rights and good governance in South Africa (Achmat, 2003). In short the TAC has been concerned with building up an awareness of HIV/AIDS issues while explaining these 'clearly and rationally in layman's terms to the public' (interview, Mbali, 21 April 2004).

To do this however the TAC has had to inform and educate the majority of its staff and members in the complexities of the HIV/AIDS discourse. The emphasis, at least from the perspective of the TAC, of the importance of treatment literacy cannot be understated, and its relation to the idea of political activity is clearly underlined:

> In TAC you will find that at provincial level [for example] our leaders will know about the Medicines Control Council (MCC). For me citizenship is not about nationality, citizenship is about participation and understanding. I think our leadership and our members understand that we have become citizens rather than subjects, citizens rather than recipients of the beneficence of the state or of corporations (interview, Achmat, 7 July 2004).

It is through the branch and community based structure of the TAC that information regarding HIV/AIDS issues is disseminated. Here it is necessary that TAC members are themselves trained in order to put a treatment literacy campaign into operation. It is for this reason that the organisation's campaign is understood to be the 'first and most important function of a branch' and 'knowledge' to be one of the most important benefits any TAC member receives (Achmat, 2003: 7). Though the organisation has relied on doctors, nurses and scientists to oversee matters of health, the nature of HIV/AIDS has presented a series of demanding challenges. In confronting these challenges, TAC members have sought to become 'experts' with regards to how medicines can be used to improve the health of people and communities (Mthathi, 2003: 9). In this respect the TAC has seen the need to compliment the efficacy of ARV medication with the appropriate knowledge of its administration and use. Therefore, the TAC has sought to inform citizens and communities about a number of issues related to HIV/AIDS, some of these including the short and long term side effects of ARV medication, when and how to take such medication and what kinds of foods and alternative medication could compliment and increase the efficacy of such medication.

A central aim behind the TAC's literacy campaign has been the idea of community empowerment. Empowerment, in this sense which is understood as enabling TAC members, citizens and communities to understand the complexities of HIV/AIDS and treatment. In this respect, the TAC has tried to empower people by helping them to understand the scientific discourse of HIV/AIDS, although not simply to understand it but to use this information in the demand for treatment (interview, Devenish, 22 April 2004). Though there is a substantive reliance on the postulates of science 'the TAC does not leave decisions to the experts'; rather, members are educated 'in the best scientific traditions to understand medicines and society' (Achmat, 2003: 5). As a result the organisation's literacy campaign has attempted to try and link the postulates of HIV/AIDS science with a broad-based community understanding of the disease. By

educating people about the science of HIV/AIDS the TAC has sought to diminish the divide between scientific expertise and the treatment illiteracy of the populace.[24]

Through the TAC's literacy campaign citizens are empowered with the capacity to make informed decisions about HIV/AIDS issues. This empowering capacity can be translated into the ability of citizens to take control of their daily activities, such as in the demand for treatment or possessing the awareness of the legal right to public health services. The democratic meaning in this observation further suggests that citizens are able to influence or even determine a public policy issue by virtue of their knowledge of a given subject. Here a set of demands directed at the government are those based on the relevant scientific knowledge, as in the case of the submissions made to parliament by the TAC with regards to HIV/AIDS policy reform. It is in this respect that the TAC can be said to invigorate a popular-democratic idea of civil society. This is because the political quality that is inherent in the initial conception of civil society is once again prevalent in the treatment and literacy campaigns of the TAC. Thus far it can be claimed that the TAC as an organisation of civil society has been heavily politicised in its (confrontational) stance towards government. Of importance here has been the capacity of citizens to take control of their daily affairs as well as to determine or influence a policy decision that has a possibly significant impact on their lives. More specifically it is suggested that the TAC has further substantiated a condition of active citizenship, whether it be through civil disobedience campaigns, or being informed enough to engage experts (both political and scientific) on a more or less equal footing with regard to public health issues.

[24] In the last half of the 20th century the role of government has become increasingly orientated to providing and implementing a number of general public services at both a local and national level (DeSario & Langton, 1987a). From a Weberian perspective the allocation and distribution of these services has been organised in a way that renders the maximum benefit at the least amount of cost. As a result an enormous emphasis has been placed on the rational and analytic techniques of public policy decision-making (Kweit & Kweit, 1987). It is in this context that modern political systems are considered to be bureaucratic: they rely upon the most efficient techniques and methods to streamline the policy making process. One particular feature of this form of decision-making is the reliance upon the expertise of science and technology. Often scientists are simply included in the offices of government itself thus rendering the expert part and parcel of the decision-making process. In an ideal bureaucracy citizens are excluded from participating directly in the political structures since they cannot lay claim to technical expertise. By educating its leaders, members and the broader community about HIV/AIDS and treatment the TAC has attempted to overcome the inequalities present in the division between expertise and lay knowledge.

Chapter 4: AIDS Activism in a Post-TAC Society?

1. Introduction

In this chapter a popular-democratic perspective will continue to frame an understanding of the TAC's 'success'. In Chapter 3, it was discussed how the TAC employed a number of strategies in pressuring the South African government to reform its HIV/AIDS treatment policy. These strategies, it was argued, were significant in that they embodied a participatory mode of politics, where TAC members sought to influence an important health issue that had an impact upon their lives. It was also suggested that these strategic initiatives were taken from an earlier period of AIDS activism in the United States. In this chapter a more critical analysis will be presented of the TAC, in which it is argued that the organisation's treatment campaign has differed markedly from the AIDS activism that was initially witnessed in the 1980s. From this critical point of departure, it is also queried as to whether the TAC has indeed enabled South Africans to participate in a number of issues related to the treatment and management of the AIDS epidemic.

In the previous chapter it was noted how the social activism of the United States AIDS movement sought to challenge the profit-driven imperatives of industrial science and research, as well as contest the cultural and moral conservativism embedded within the AIDS establishment. Mapped out on a continuum ranging from the political 'left' to the 'right', the early period of AIDS activism in the United States was for the most part aligned to the 'left' of the United States government and the scientific and medical community. As in that country, a similar kind of confrontation has arisen in South Africa between an AIDS activist movement – the TAC – and the supposed 'establishment' – the government. Along this political continuum, however, the orientation of both the TAC and the government has been noticeably reversed. As pointed out by Neocosmos (2004), such is the nature of the South African government's position on HIV/AIDS treatment that it can be situated to the 'left' of the TAC and the scientific and medical community.

What situated the AIDS movement on the 'left' in the United States was its radical critique of the institutional basis of science and medicine, and the moralistic and conservative stance of the Reagan government . Having witnessed the unwillingness of

the scientific establishment to urgently respond to the onset of the epidemic and the manner in which medical practitioners contributed to the stigmatisation of gays, AIDS activists sought to refute the epistemological claims of science to be free from the extraneous political or cultural 'contaminants' of society. Activists came to see the scientific explanation and management of AIDS as nothing short of a biased cultural (as opposed to an objective and medical) response to the disease. As a result, activists and scholars came to assume a particularly post-empiricist view of the HIV/AIDS as the first decade of the epidemic came to a close:

> AIDS does not exist apart from the practices that conceptualise it, represent it, and respond to it. We know AIDS only in and through those practices. This assertion does not contest the existence of viruses, antibodies, infections, or transmission routes. […] What it *does* contest is the notion that there is an underlying reality of AIDS, upon which are constructed the representations, or the culture, or the politics of AIDS (Crimp, 1988a: 3).

In other words, AIDS was not considered by activists in the 1980s in the United States to be simply the term for a new disease presented to the public by scientists. Taking from the work of cultural studies, sociology, linguistics and anthropology, activists came to understand 'AIDS' as a symbolic artefact of the cultural and social practices of a given society. Science was just one of these practices and therefore could not assert itself as the 'true material base' generating an objective and scientifically determined 'reality' of the disease (Treichler, 1988: 40). As Epstein (1996: 35) remarks, this questioning of science's privileged position was seen as an attempt to change the 'ground rules for the social construction of belief' about HIV/AIDS. From this point of departure, AIDS activists sought to challenge 'the powerful and deeply entrenched social and historical codes' of the scientific and medical establishment. Through intense political activism, campaigning, and self-education, organisations such as ACT UP were seen to confront the AIDS establishment by advocating 'a counterhegemony to the prevailing social understanding of AIDS' (Conrad, 1997: 60). AIDS activists thus sought to understand the cultural processes underlying the production of knowledge in order to target the

procedures, techniques, content, authority and autonomy of the scientific and biomedical framework.

Put in this way, the subject of HIV/AIDS, metaphorically speaking, can be seen as the terrain upon which social actors (the AIDS activist movement and the 'establishment') have produced and contested various representations and practices of HIV/AIDS. In this regard, it would not be inaccurate to frame this terrain, *vis a vis* Foucault, as a discourse. As Foucault has argued, the term 'discourse' embodies something more than just the act of conversation, deliberation, or analysis of text (Foucault, 1980). Rather, discourses can be thought of as 'well-bounded areas of social knowledge' that are spoken, written and thought of in certain ways, and not others; where bodies of knowledge are not only produced and practiced within the contexts of specific historical conditions, but are also ranked hierarchically or simply excluded from the records of history altogether (McHoul & Grace, 1993: 31). When viewed from this perspective the subject of HIV/AIDS raises a number of important questions. For example: How and why is knowledge about HIV/AIDS being produced in the way that it is and who is contributing to this body of knowledge? What are the existing discourses in which HIV/AIDS is mentioned? To what extent is there a hierarchy of discourses on HIVAIDS and what kinds of recourses are required to sustain the authority of a dominant discourse? How do discourses work to articulate, codify, maintain, or challenge various forms of authority, power and control over material resources with regards to HIV/AIDS? And, how do discourses empower people and people empower discourses? (Treichler, 1992; Erni, 1994.)

2. The Discourse of HIV/AIDS in Post-Apartheid South Africa

In South Africa, a 'confrontation of discourses' has emerged in which two positions have differed over a central question concerning the most appropriate and effective response to the HIV/AIDS epidemic? This first position, represented primarily by the TAC, the media, certain factions of civil society and the medical community, can be described as the Western, hegemonic and scientific discourse of HIV/AIDS. This position sees a biomedical response to the disease, via the provision of ARV medication as *the* feasible solution to the HIV/AIDS disease. The organisation has therefore situated the disease in a 'scientific paradigm' and used the tenets of 'science to reinforce its own

arguments' (interview, Devenish, 22 April 2004). The second position is represented by the South African government, the ANC and various other marginal factions, the most well known of these being a group of scientists, referred to by the TAC and the media as 'dissidents' or 'denialists' who question the contagion HIV causes AIDS hypothesis. The common link within this position can be located in the rejection or, at least the, scepticism of the dominant scientific discourse, which considers HIV/AIDS to be a medical problem, or disease curable by the invention of some vaccine, or by the development of an advanced series of medical intervention programs.

It is possible to claim that Mbeki and the ANC have been fully aware of the debate and the confrontation of discourses regarding the subject of HIV/AIDS.[25] It is apparent, however, that the president was not fully aware of the reaction his position would cause when he decided to publicly debate the theory and treatment of HIV/AIDS. Like Mbeki, the ANC has been equally concerned that much of the debate surrounding HIV/AIDS treatment has been grossly misrepresented and oversimplified by the media, which has sought to bring about the 'willful encouragement of hysteria' (ANC spokesman quoted in the *Star*, 3 December 2001; *ANC Today*, 2001a, 2001b). Thus, when Mbeki first announced his views on the subject in 2000, he remarked how surprised he was at the 'storm' that broke out over his position on the HIV/AIDS issue (Mbeki, 2000). The president went on to say that it was an irony that 'people who otherwise would fight very hard to defend freedom of thought and speech occupy the front-line in the campaign of intellectual intimidation and terrorism' (Mbeki cited in South African government, 2000). Mbeki said that the controversy generated around the HIV/AIDS issue was situated in a 'slogan' that theorised HIV as the cause of AIDS and that any attempt to address the nature of AIDS in an alternative or more comprehensive manner would be viewed as the 'questioning [of scientific] orthodoxy' (South African Government, 2001). Relating specifically to his right to ask questions about the science of HIV/AIDS, Mbeki disagreed with accusations that he was betraying the people by looking at some 'obscure scientific theory' (Mbeki, 2000). Mbeki suggested that 'there exists a scientific view that is

[25] See for example the remark in an ANC online article stating that the HIV/AIDS debate in South Africa has been focused on a medical response to the epidemic via the provision of ARV therapy to HIV-positive pregnant women, survivors of sexual assault and people in the advanced stages of AIDS (ANC Today, 2001a).

supported by the majority who 'argue that the only freedom we have is to agree with what they decree to be established scientific truths' and that the government cooperate with scientists 'to freeze scientific discourse on HIV/AIDS' (South African Government, 2000).

> I don't know of any science that gets resolved in that manner with a cut-off year beyond which science does not develop any further. It sounds like a biblical absolute truth and I do not imagine that science consists of biblical absolute truths. […] Perhaps that is why you had that kind of response which sought to say: let us freeze scientific discourse at a particular point; and let those who do not agree with the mainstream be isolated and not spoken to. Indeed it seems to be implied that one of the important measures to judge whether a scientific view is correct is to count numbers: how many scientists are on this side of the issue and how many are on the other - if the majority are on this side, then this must be correct (South African Government, 2000a).

Mbeki sought, in a similar manner to that of the AIDS activist movement in the United States, to 'question not just the *uses* of science, not just the *control over* science but sometimes the very *contents* of science and the *processes* by which it is produced' (Epstein, 1996: 13). And, in the same way that the medical community was accused of bias and discrimination towards gay people in that period, Mbeki has likened the TAC's alliance with the hegemonic scientific discourse of the West as akin to the epitome of the anti-democratic ideal – apartheid. The aggressive manner in which the TAC has sought to defend the scientific and biomedical discourse while dismissing alternative viewpoints on the subject of HIV/AIDS has led Mbeki to remark that 'we are now being asked to do precisely the same thing that the racist apartheid tyranny did because, it is said, there exists a scientific view that is supported by the majority, against which dissent is prohibited' (South African Government, 2002a). From this point of view, the government has claimed that the campaign waged by the TAC has prevented a constructive dialogue on the subject of HIV/AIDS and thus the development of an African-specific response to the epidemic (Mbeki in the *Sunday Tribune*, 7 April 2002).

This interpretation has been rejected by civil society, particularly the TAC and the media, by arguing that Mbeki's views are misinformed and at odds with the accepted scientific understanding of HIV/AIDS. Mbeki's stance on ARV treatment has been described as 'irrational' (*Daily News*, 13 March 2002), 'warped' (Mbali, 2002: 2), 'arrogant' (Trevgrove-Jones in the *Mail & Guardian*, 5 October 2000) and even 'evil' (Achmat in the *Cape Argus*, 8 October 2001). Tom Masland (Gevisser in the *Newsweek*, 4 March 2002) has explained Mbeki's 'obstinate refusal' to acknowledge the HIV/AIDS crisis as the outcome of a life history which predisposed him to tendencies of 'paranoia'. The president's views have also been dismissed on the basis that he lacks the intellectual capacity as a scientist and is therefore not in a position to make suggestions on appropriate HIV/AIDS treatment programs. (See, for example, Esack's remark (in the *Pretoria News*, 8 October 2001) comparing Mbeki to those who continue to think that the earth is flat in an obvious attempt to equate the president's intelligence with those in early middle ages, or with those remaining few individuals who continue to view the earth as a non-spherical object.) The TAC and the media have reserved much of the same type of criticisms for those critical of the dominant HIV/AIDS discourse: the South African government has been accused of being in denial' (*Cape Argus*, 21 September, 2001); the Minister of Health, Tshabalala-Msimang, has been described as 'arrogant' (interview, Devenish, 22 April 2004), 'irresponsible and nonsensical' (*Star*, 17 February 2004); Khulekani Ntshangase, the ANC Youth League spokesman, has been ridiculed as a 'clown' (*Mail & Guardian*, 1 May 2004); Riaan Malan has been described as an 'acolyte' of Mbeki (interview, Achmat, 7 July 2004); and the sociologist Susan Zeihl has been described as a 'crypto-denialist' (someone who conceals his/her identity as a denialist) (interview, Achmat, 7 July 2004).

3. Democracy, Civil Society and Citizenship: Confronting the HIV/AIDS Epidemic

The TAC's response to those critically orientated to the dominant discourse of the disease is of importance, for the organisation has attempted to control, regulate and (de)legitimise the participation of various factions in the HIV/AIDS debate. More significantly, the organisation has attempted to deter the prospect of constructive dialogue concerning a number of issues related to HIV treatment and medication, strongly

implying that the discursive terrain of the disease be accessible only to those willing to speak and practise in the name of the 'good' (Achmat, 2003: 5) or the 'serious' (interview, Achmat, 7 July 2004) science of HIV/AIDS. These descriptive terms ('good', 'serious') are particularly indicative of the TAC's strategic use of a 'true' scientific discourse and the rejection of the 'bad' science, or the 'false' discourse of the government. For the most part, those persons or groups who have embraced the 'bad' science of HIV/AIDS have been dismissed by the organisation as 'denialists', a term used to label those (be it scientists, journalists, academics or government officials) who allegedly deny the 'reality' of the HIV/AIDS epidemic.

It is suggested here that the charge of 'denialism' has been the most effective way to regulate the participation of certain factions in the discourse of HIV/AIDS. For this reason the label has often been used against dissenting voices. This observation can be strikingly illustrated in the references to Mbeki and the government's position of the science of HIV/AIDS. The label 'denialism' has also been made in reference to the notion of democracy. It is from this juncture that analogies have been drawn between Mbeki's views on HIV/AIDS and the autocratic rule of apartheid and President Robert Mugabe of Zimbabwe, Nazism, the holocaust and genocide (see for example, Geffen in the *Sowetan*, 25 February 2004; Nyatsumba in the *Daily News*, 13 March 2002; Moore in Bethell, 2000). According to some commentators, it is the 'totalitarian mindset' (*Natal Witness*, 18 December 2001) of Mbeki's views and the government's HIV/AIDS program which have ignored the principles that lie 'at the heart of all humanity' (*Mail & Guardian*, 6 December 2001). Stating that the 'clearest indication of the health of this democracy is to be found in discourse surrounding the HIV/AIDS pandemic', Trengrove-Jones (in the *Mail & Guardian*, 5 October 2000) argues that Mbeki and the government's position on ARV treatment was jeopardising South Africa's democracy.

> The president is not the minister of health, nor is he a medical scientist. It is a travesty of democratic governance for preventable deaths to occur because of the intransigence of one very powerful and intellectually arrogant man. The existing AIDS program and the toadying to people in power, are a slap in the face to all

> those who fought against apartheid to bring dignity to the poor and dispossessed in this country (Jones in the *Mail & Guardian*, 5 October 2000).

One TAC member has sought to frame Mbeki's 'denialism' in terms of a broader 'African Nationalist' project (Mbali, 2002: 8). Mbeki's position on HIV/AIDS, according to Mbali, is a reaction to a 'racist' and 'neo-imperial' scientific/biomedical framework in the colonial and apartheid periods which saw Africans as inherently predisposed to sexual deviance. According to the author, Mbeki's 'denialism' is thus an 'attempt to re-mould images of African sexuality, by denying the veracity of mainstream Western biomedicine's model of AIDS' (Mbali, 2002: 17). An attempt, Mbali (2002: 17) asks, 'to redefine South Africa[n] nationhood and the body politic, in terms of his misty concept of the 'African Renaissance'?' While Mbeki has indeed tried to revoke images of African sexuality as 'promiscuous germ carriers', and has indeed attempted to propagate an African solution to HIV/AIDS (which has never been clearly articulated), the essential point of Mbali's is one that juxtaposes the presidents 'misty' (2002: 2) nationalist ideology with a modern liberal discourse, his government's 'irrational' (2002: 18) stance on HIV/AIDS with a 'rational' HIV/AIDS policy grounded in a bio-medical and rights-based model, and his 'wrestling with the ghosts of colonial medicine' with the 'predictive and interpretative power' of modern Western science (2002: 22). From this perspective,

> it appears that in his rhetoric he [Mbeki] has gone back to the past, as if in a time machine to argue against discourse, which for the most part has been massively surpassed in the 'AIDS world' by rights-based, anti-discrimination discourse and a shift to a medical, technical, non-'moralistic'/stigmatising approach. Mbeki is arguing against a delusion of his own making… (Mbali, 2002: 18)

In this instance Mbeki is presented as a man out of touch with the current times and exercising a logic that is idiosyncratic with the progressive and scientific logic of modernity. As a result the success of the TAC has been understood in terms of bringing Mbeki and the government in line with a 'modern' worldview that is not historically

fixated but progressive, not traditional but rational, not ideological but scientific, not authoritarian but democratic. [26]

These sorts of discursive attacks, which are directed at factions critical of the dominant consensus of HIV/AIDS, should be deconstructed here. It should be noted here that the aggressive defence of the postulates of HIV science are particularly antagonistic to the early AIDS activist movement at the onset of the epidemic in the United States, which sought not to insulate the biomedical establishment the general public but to force it open, to democratise the very tenants and activities of science and medicine. This point is raised by Epstein (1991: 38) with particular reference to the objective of AIDS activism:

> The struggle for democratisation might be expressed in demands that the scientific elites and institutions should be responsive to community concerns, that the public should exercise participation in setting research priorities, that popular control be established over the 'medical-industrial complex', or even that medical science should be reorganised to facilitate universal access to health care. But AIDS activism also puts a more unusual – and certainly radical – spin on the question of democracy. It maintains that grassroots activists, acting on an equal footing with the credentialed experts, can participate in advancing knowledge about AIDS; and that lay spokespersons can attain a level of qualification that permits them to speak authoritatively about scientific theories, facts, and methods.

In South Africa it is clear that the government has taken this particular task to hand while civil society, in particular the TAC, has sought to oppose it. The attempt to subject science to the logic of democracy is of importance insofar as it enables citizens to engage

[26] The response to Mbeki's position on HIV/AIDS often echoes a developmentalist paradigm in the 1960's and 70's which envisaged the transition of (African, Asian and South American) countries from a traditional, religious, communal, rural, agrarian, rural, patriarchal based society to a modern, secular, liberal, urban, industrial and democratic society respectively. Those countries still in a 'pre-modern' phase of development would have to progress politically (transition to democracy), economically (transition to industrialism and capitalism) and socially (transition to a liberalism) to enjoy a modern status with their counterparts in the West. Mbeki's views have been likened in a similar manner to the state of 'pre-modern' societies. Here Mbeki, from the sentiments of his critics, seems to be trapped in a particular ideological state that can best be described as 'backward', 'traditional', 'authoritarian', and so on – basically the vices that are to the contrary of modern progressive thinking.

medical experts in the social and cultural construction of knowledge. However, it is to be noted that the practice of science and the notion of democracy are not the most comfortable of 'bedfellows'. As McRae (cited in DeSario and Langton, 1987b: 206) observes:

> science and democracy symbolise alternative modes of guiding society. Until recently they were believed to have supported one another; science enlightened the public and provided it with new alternatives, while democracy allowed science to flourish. But in recent years, the values of science and democracy have increasingly appeared to conflict, especially in their application to public choices. Insofar as public choices depend on expert information, science requires that this information be judged by experts rather than the electorate. Democracy, however, requires that the electorate have the ultimate power.

From this observation the possibility that citizens can in some way or another participate in the science of HIV/AIDS becomes problematic. This is because the nature of the scientific realm is open only to those who possess the appropriate expertise and scientific knowledge about the subject in question. As a result, citizens find themselves isolated from actively partaking in the affairs of HIV/AIDS as experts assume the right to make decisions on behalf of the populace. In this respect it is possible to claim that the nature of the scientific discourse diminishes the capacity of citizens to actively participate in the decisions that affect their lives. The appeals to leave 'science to the scientists' thus reveals a somewhat conflicting attitude to the spirit of AIDS activism and the possibility of lay participation in science. Citizens are simply to agree with the science of HIV/AIDS; if not, then those with alternative perspectives are excluded from participating in the subject of HIV/AIDS by virtue of being arbitrarily labelled as 'dissidents' or 'denialists'. The 'dissident' scientific perspective should not simply be seen as the binary opposite of the dominant or mainstream scientific discourse of HIV/AIDS, nor should it only be qualified in terms of its distance from the 'true' discourse of AIDS. If discourses are practices based on cultural constructions then the absence of a stable and absolute reference point precludes the capacity to qualify a given

discourse over and above another. The argument for or against epistemological relativism is not being made here. Rather, the concern is when certain discourses are subjugated to the point where the participation of individuals in the construction of knowledge is severely limited or prohibited from the outset.

The TAC has argued that the subject of HIV/AIDS be left to the mainstream scientific view, and that the latter should inform government policy where and when necessary. However, as this study has attempted to argue, a popular-democratic perspective of civil society is one in which the capacity of citizen participation in policy-making decisions is enhanced or substantiated. This particular understanding derives principally from the formulation of civil society as a community of citizens with the capacity to engage in the political affairs of the state, as well as participate directly in the process of government and rule. From the discussion presented so far, can it be claimed that the South African government has contravened this democratic principle by excluding citizens from the HIV/AIDS decision-making process? And is it simply the case that the 'success' of the TAC has enabled civil society to participate in the formulation of an appropriate (treatment) response to the epidemic?

This study suggests that in a post-TAC society citizens are likely to be limited in their capacity to assess the means by which the government's HIV/AIDS policy is shaped. Furthermore, the subject of HIV/AIDS will continue to remain outside the reach of ordinary citizens, specifically in terms of their capacity to play a role in the way that responses to the HIV/AIDS epidemic are constructed. These two conditions, it is suggested, are primarily the result of the TAC's 'success' in pressuring the government to reform its HIV/AIDS treatment policy. Ostensibly, what the TAC successfully demonstrated was its ability to force the government's HIV/AIDS treatment policy into the public realm where it could be contested and then subsequently reformulated by citizens and organisations of civil society. However, it should be pointed out that the discursive nature of the TAC's campaign did not intend that the subject of HIV/AIDS remain there. Rather, it is argued that the organisation sought to instead remove the subject of HIV/AIDS from the public realm by insulating it within the institutional domain of the scientific and biomedical establishment. This observation can be clearly witnessed in the manner that the organisation (with the assistance of the media) has

vigorously advocated that HIV/AIDS is not the topic for public debate and that science be unhindered in the formulation of its response to the epidemic. What is it that is so problematic about this facet of the TAC's 'success'? The concern can be stated as follows: whereas the public realm offers citizens the opportunity to shape and influence the decisions government makes with regard to HIV/AIDS, the scientific realm does not enable that its procedures, activities and practices be contested by the layperson: its means are limited specifically to those who possess the appropriate medical expertise and scientific knowledge about the subject in question.

It is often argued that matters of importance be left to the expertise of science of medicine, that the latter should inform government policy where and when necessary. However, from a substantive definition of democracy (as opposed to a minimalist one) it is argued that the populace (rather than the scientific elite) in dialogue with the government act to formulate appropriate public policies. Through a self-empowerment model of community organising, the mainstream practice of science is democratised from below as citizens attempt 'to take control of their own medical matters' (Erni, 1994: 57). However, such has been the response (by the TAC and the media) to the attempts to present alternative views to the mainstream science of HIV/AIDS that such a scenario seems almost inconceivable. This understanding is essentially a reference to the discussion that was put forward in Chapter 2: a popular-democratic formulation of civil society is one in which citizens act to participate in the process of rule and government, on the one hand, and in the public affairs of the state, on the other hand. In South Africa, however, this principle has been overshadowed by the attempts of the TAC and others to force the government to co-operate with an elite group of scientists and medical practitioners in the formulation of an HIV/AIDS treatment policy. To what extent, then, have South African citizens been able to play a part in the formulation of the government's HIV/AIDS policy?

The recent findings of an article appearing in a journal called the *Afrobarometer* (2004) can be used to illustrate the discussion presented above. In a study conducted across 15 African countries it was found that despite being exposed to the HIV/AIDS epidemic only one in ten people considered AIDS to be among the top three pressing concerns in their respective countries, poor people demoted AIDS to a low priority status,

and citizens were undecided as to whether governments should devote scarce resources to fight HIV/AIDS (Afrobarometer, 2004). In South Africa 26% of the respondents believed HIV/AIDS to be a top priority health issue, while 40% believed that government should devote more resources to HIV/AIDS in contrast to the 43% of respondents who said that resources be devoted to other problems. The article further stated that 'those who have experienced loss are *more* likely to cite AIDS as a national problem requiring government attention, those who suffer higher levels of lived poverty are *less* likely to cite the issue' (Afrobarometer, 2004: 5).

With this above cited study in mind it must be asked whether the emphasis on the question of HIV/AIDS and treatment has been supported by the majority of South African citizens. More specifically, it must be queried whether the TAC has acted in the interests of civil society itself; if not, then whose interests has the organisation represented? In many respects the TAC can be said to support an urban, and substantially white, middle class support base; whereas the government's constituency is primarily black and lower class. It for this reason that some members in the TAC leadership have encountered resistance and opposition on occasion from black South Africans. As the treasurer for the TAC, Mark Heywood, in attending a NAPWA (an AIDS activist group calling themselves the National Association for People Living with AIDS) conference recounts:

> Apart from their general unruly and threatening conduct it is necessary to report and condemn the racism that is being formented and encouraged by NAPWA's leadership. The very first comment by a NAPWA member during the meeting included a racist attack on a white member of the AIDS Consortium Executive, Chloe Hardy, who was told that 'we are sick of white people sitting at the front of the meeting; it causes us pain.' to applause from the NAPWA leaders. At the end of the meeting Thandoxolo Doro, the national organiser of NAPWA, confronted me aggressively and shouted in front of other people 'we are sick of you fucking white racists taking advantage of black people and people with HIV/AIDS.' As he and other NAPWA members advanced on me I was removed for my safety from the meeting by an employee of COSATU and others. After the meeting had ended, the

> NAPWA members toyi-toyied in the meeting room and outside led by NAPWA Director Nkululeko Nxesi, singing 'Mark Heywood the white racist has succeeded in dividing black people - that was his agenda all the time.' An intervention to stop this by Mazibuko Jara, the Chairperson of the AIDS Consortium, led to a new chant that Jara was the new 'black bourgeoisie.' The last person to make a racist attack on me was the Minister of Health who, in April 2003, attacked me in a public speech as the 'white man misleading black people in TAC to demonstrate against the government.' (TAC, 2004b).

In rural communities, resistance to the TAC has been documented, as displayed by the brutal slaying of an AIDS activist in Gugulethu, and the refusal of CBOs (community based organisations) and NGOs to form alliances with the TAC in the townships as well as in the rural areas (interview, Zitha, 30 June 2004). Can the point to be made that a lack of popular support exists for the TAC's motives to reduce the government's policy to a specific question of ARV medication? And from this suggestion can it be further suggested that the TAC's 'success' has restricted the government's capacity to form its HIV/AIDS policy according to the mandate of its constituency?

4. Poverty and ARVs: Citizens and the Response to the HIV/AIDS Epidemic

In South Africa, the role of poverty in the incidence of HIV cases has been a central point of contestation in the HIV/AIDS debate. It is also the reason that led Mbeki to first conclude that 'a simple superimposition of Western experience on African reality would be absurd and illogical' (South African Government, 2000a). Mbeki has argued that the socio-economic condition of poverty has been the principle contributing factor in the onset of the HIV/AIDS epidemic. By dismissing that 'world's biggest killer [AIDS] and the greatest cause of ill health and suffering across the globe, including South Africa' could be 'blamed on a single virus' (Mbeki, 2001), Mbeki has sought to challenge the 'approach which seeks to make the disease just a health problem' (government spokesperson quoted in *Business Day*, 20 March 2000). On this basis both the President and the Minister of Health in South Africa have defended their right to seek solutions to the HIV/AIDS epidemic outside of the dominant scientific opinion.

> The interests of public health and those of our people are better served by government investing in the all-round development of a robust public health infrastructure and health system to better confront the many diseases we face – such as TB, malnutrition, malaria, cholera and opportunistic infections – as opposed to spending all our limited resources on the purchase of antiretrovirals (*ANC Today*, 2001c: 5).

Though the TAC has not denied the impact of socio-economic factors related to the disease, the organisation has criticised the government for speaking of 'poverty, transformation and delivery as a national issue rather than HIV' (Heywood in the *Sunday Tribune*, 30 April 2003). The TAC's position on the relation between HIV/AIDS and poverty is determined principally on the scientific postulate that AIDS is caused by the HI virus, and that social issues such as poverty, gender inequality, migration, and prostitution, for example, play a secondary role in terms of increasing the likelihood of HIV transmission (interview, Achmat, 7 July 2004; interview, Mbali, 21 April 2004; interview, Zitha, 30 June 2004). The TAC's understanding of HIV/AIDS can be said to emanate from a discourse in which a scientific and biomedical worldview 'constructs a particularly narrow definition of disease that separates it from social sources and consequences and studies it as a discrete abnormality in biological structure and functioning' (Kleinman cited in Farmer *et al.*, 1996: 198). Such an understanding suggests that the HI virus be decontextualised from the broader structural and social nexus from which the character of the HIV/AIDS epidemic is derived. This understanding of the HIV/AIDS, which Farmer *et al*. (1996: 198) describe as the 'desocialisation of a very social pandemic', ignores that HIV/AIDS is deeply embedded in what the immanent sociologist C. Wright Mills (1959: 5) has called the 'larger historical scene'.

The TAC's 'single-issue' campaign has endeavoured to frame the solution to the HIV/AIDS epidemic in the availability and provision of ARV medication. This objective was first witnessed in the organisation's campaign with the pharmaceutical industry and then with the South African government for the access to cheaper, and later, free

medicines. Because of the government reluctance to comply with the TAC's demands, the HIV/AIDS debate in this country became consequently fixated for a long period of time (1998-2004) on the availability and accessibility of ARV medication. In effect, once the government was sufficiently compelled to align its treatment policy with the orthodox scientific model of HIV/AIDS the social, historical or political issues directly related to the disease became effectively reduced to the logistical complications of implementing an ARV treatment program. As a result, in South Africa the debate, which was rightly grounded on the question of 'What is the best response to the epidemic?' turned to the question of 'How can people living with HIV/AIDS access ARVs?' to finally end at the concern of 'How can the institutional process for providing HIV medication be hastened?'

In light of these observations how can the government's arguments that socio-economic factors such as poverty be taken into consideration when responding to the epidemic? In sociological terms, the socio-economic or structural conditions of poverty are measured not in terms of paucity of consumption but by social participation. Poverty is a condition that leads to the exclusion of citizens from the 'mainstream way of life and activities in a society' (McCally *et al*., 2000: 6). It is ironic (because it should be the task of organisations of civil society) that the South African government has in fact advocated that citizens pro-actively respond to the day-to-day issues of HIV/AIDS. This can be clearly seen in the government's call to citizens to establish vegetable gardens and combat AIDS by eating such 'immune-boosting' foods such as garlic and the African potato. The fact that these suggestions have been ridiculed particularly by the TAC and the media underscores the observation that the government has been to the 'left' of civil society in mobilising citizens to proactively address the impact of the disease. At its most intense, the political capacity of civil society, as advocated by the TAC, becomes simply a case of attending task teams that monitor the progression of an ARV rollout plan, displaying a willingness to be educated about the science of HIV/AIDS, and remaining ready for the call to mobilise should government remit on its treatment obligations. Where citizens could have mobilised to pressure the government to improve sanitation in local communities, or subsidise the growing of fresh produce, citizens in a post-TAC society are now expected to passively await the distribution of ARV medication at public

health facilities (Neocosmos, 2004). Citizens are expected to return to the daily affairs of their lives; content that sooner or later they will be able to access ARV medication. In effect, following the success of the TAC, civil society is expected to perform a liberal function. Here, civil society, after having demanded that government realise its constitutional duty to provide public health care – a socio-economic right of citizens – disengages from the political sphere until it is necessary to confront government again in a similar instance.

5. HIV/AIDS in a Post-TAC Society

It is in this respect that the TAC has taken a particularly 'liberal' view of the epidemic: 'that there are, on the one hand, the scientific facts about AIDS and, on the other hand, ignorance or misrepresentation of those facts standing in the way of a rational response' (Crimp, 1988a: 3). The organisation has seen the government's position on the science of HIV/AIDS as an obstacle to what it considers to be the rational response to the epidemic – the implementation of a countrywide ARV program. But it is specifically for this reason that the TAC has failed to understand the concerns raised by the government in implementing such a program. It is unlikely that much progress will be made to manage and treat HIV/AIDS so long as the government's position on HIV treatment is seen as a problem *obstructing* a 'rational' response to the epidemic. What must be realised, and it hoped that this study may have suggested this point on a more subliminal level, is that the government's ambiguous as well as perplexing response to the epidemic has been *part* of the problem of HIV/AIDS itself. This statement should be clear enough in light of the delays by the government in implementing an ARV rollout program (despite being ordered to do so more than two years ago by the courts); the structural logistical, socio-economic factors which limit the distribution of HIV medication effectively; the persisting suspicion of Western medicine, questions which still surround the efficacy and toxicity of Nevirapine; the existence of AIDS-related stigma in communities; misinformation and cultural beliefs which cloud an understanding of the science of HIV/AIDS in many African communities; the reluctance of people to volunteer for HIV testing and counselling, and so on.

It is perhaps the TAC's 'liberal views' (to quote Crimp again) that has prevented the organisation from accurately framing the government's position on HIV/AIDS (by misusing the term denialism to explain the latter's response). More importantly the organisation has failed to realise that the 'lack of political will' (interview, Nkala, 22 April 2004) displayed by the government in implementing an ARV program is a much a part of the difficulties in responding to the epidemic as poverty, sexual promiscuity, stigmatisation and the lack of health service infrastructure are. In other words the TAC's 'success' cannot be simply measured from a neo-liberal perspective in terms of pressuring the government to reverse its stance on HIV/AIDS treatment. As has been argued throughout the course of this study, this understanding is not sufficient in its explanation as to why the organisations efforts should be seen as a 'victory for civil society and democracy' in this country. This study has called for an alternative and more critical perspective as a means to providing a clearer understanding of the politics of HIV/AIDS in this country. If the media, academia and civil society continue to approach the disease in the manner that they have then it is likely that the South African government's past as well as current responses to the epidemic will continue to baffle those who are concerned about the crisis of HIV/AIDS in this country.

Conclusion

In this study an attempt has been made to provide a theoretical discussion of an important concept: civil society. Furthermore, this discussion has been framed within the post-apartheid context by selecting the case of the confrontation between a prominent AIDS activist organisation, the TAC, and the South African government. The eventual 'success' of the former in pressuring the latter to reform its controversial HIV/AIDS policy was seen by many to be a victory for civil society and democracy in this country. In the introduction of this study it was noted that this popular interpretation of the TAC's 'success' emerged from a neo-liberal perspective of civil society. By pointing out a number of theoretical inadequacies in this framework, an alternative and critical reading of the term civil society as well as the TAC's 'success' was presented. It is from this methodological point of departure that the case of the TAC-government confrontation was used to advance the argument for a popular-democratic perspective of civil society.

In contemporary sociological and political science literature, the concept civil society is often formulated within a neo-liberal theoretical framework. Here, civil society comes to be defined as a heterogeneous and pluralistic association of non-profit organisations residing outside the domain of the state. This definition also conceives civil society to be a realm in which citizens are entitled to a set of legal, social and political rights. The nature of civil society is further understood to be autonomous and independent in its relation to the state. There is, in this sense, a rigid separation between society, which is safeguarded by civil society, and a political society, represented in this case by the state. Here, civil society acts as a counterweight to the state: it decentralises state power and operates to prevent the state from intruding on the freedom and individual rights of citizens. Civil society can also place demands upon the state and even engage the state in a confrontational manner when necessary (as the case of the TAC illustrates). As was discussed in Chapter 2, this perspective tends to provide a limited understanding of the power of civil society in the transition to democracy, on the one hand, and its role in established democracies, on the other hand. This argument reveals the limitations of a neo-liberal framework in its account of civil society, democracy and citizenship, an understanding which is problematic in that is presents citizens as passive political actors

and reduces the notion of democracy to a rights discourse. Furthermore, the current neo-liberal emphasis on the term 'pluralism' cannot adequately explain why a heterogeneous collection of associational relations should be seen an indication of the strength or depth of democracy in a given social context. The argument that the depth of democracy can also be measured in terms of a plurality of relations between the state and civil society does not help to explain this theoretical inadequacy either.

In this study I have argued that an alternative reading of the term civil society be presented. From a popular-democratic perspective, civil society is understood to be a realm of political activity in which citizens continually partake in the public affairs of the state. The nature of this political activity is in itself democratic for it implies the participation of citizens in the process of rule and government (taken literally from the Greek definition of 'power to the people'). This understanding further implies that citizens seek to take control of the issues that impact on the day-to-day affairs of their lives. In this respect, citizenship is a duty or obligation to oneself and community, and civil society is the realm in which this enactment takes place. Democracy, it can be said, is the process whereby citizens interact with one another and a respective ruling authority. From this point of view, the concepts civil society and democracy come to mean something more substantive than what has been portrayed be a neo-liberal perspective. Civil society in this respect cannot be defined narrowly as the non-profit sector, or as a plurality of organisations residing outside the realm of the state or the family. Nor should it be simply conceived as an autonomous realm in which individuals are guaranteed the freedom to pursue private interests, on the one hand, or are entitled to a set of legal, social and political rights, on the other. It is in this case, then, that the emphasis on the term 'pluralism' becomes redundant, as does the strict conceptual division between the state (political society) and civil society (society).

When this critical reading is applied to the politics of HIV/AIDS in South Africa the confrontation between the TAC and the government can be seen in a different light. The TAC has been portrayed as a civil society organisation or social movement confronting the government in the name of a socio-economic rights-based approach, as was witnessed in a number of court cases dating back to 2001. The ability of the TAC to legally compel the governments to reform its controversial HIV/AIDS policy was as a result proclaimed

to be a victory for civil society and democracy. While this study does not dismiss this actuality it does argue that this particular interpretation is incomplete. By applying a popular-democratic perspective as an interpretive framework, the TAC's 'success' can be opened up to an analysis that could not be undertaken from a neo-liberal framework because of its minimalist conceptualisation of the concept civil society.

In this study, then, the TAC's 'success' came to be measured in terms of the organisation's capacity to enable a substantial number of citizens to partake in an important public health issue. The positive reading of the TAC's 'success', which was presented in Chapter 3, highlighted the manner in which the organisation had indeed enabled its members and other citizens to play a role in pressuring the government to reform its HIV/AIDS policy. But it is also from this position that a critical analysis of the TAC's 'success' was presented. This analysis was situated in what Hopkins (2002a) has referred to as a 'post-TAC society'. Using a popular-democratic perspective, a number of questions were raised with regard to how South African citizens would continue to participate in a variety of issues related to the management and treatment of HIV/AIDS. A neo-liberal perspective could not adequately address these questions because of the manner in which it conceived the TAC to be a civil society organisation confronting the South African government with a set of demands when necessary. But what is the role of civil society and what are citizens to do during the time that government purports to commit itself to a 'rational' HIV/AIDS policy? Is it expected that citizens return to the private realm of their everyday lives in wait for the state to roll out ARV treatment?

In this study I have attempted to argue that the term civil society be understood from a theoretical standpoint that is at odds with a neo-liberal perspective. From this position I have further suggested that a more critical reading of the TAC's 'success' be given. In the discussion presented in Chapter 4 of this study, it was suggested that citizens actively participate in the management and treatment of HIV/AIDS by various means. While the TAC may provide a channel for such activity, other initiatives are available to citizens and people living with AIDS. Some of these may include improving dietary intake, establishing and developing vegetable gardens, campaigning in the name of poverty-related issues (for the construction of public health facilities infrastructure, improved health care and sanitation), setting up and participating in support groups, and

participating in various other community based initiatives in the name of HIV/AIDS (but not necessarily in relation to ARV treatment). While a number of suggestions were put forward in Chapter 4 it is proposed that a more thorough and in-depth analysis of a range of topics discussed in this study be investigated elsewhere. For reasons of scope these topics could not be comprehensively addressed in this study. Some of these possible topics may include a more nuanced discussion of the concepts 'civil society' and 'democracy' at both a theoretical and a ground level (by applying such an analysis in the post-apartheid context); an objective re-reading of the politics of HIV/AIDS in South Africa over the last decade; an analysis of the nature and the operation of AIDS discourses; the role of the media in disseminating information and shaping public opinion about HIV/AIDS; and an investigation into the social, cultural and traditional perceptions of HIV/AIDS within South African communities.

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Interviews

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Appendix: Interview Transcriptions

1. Interview with Mandisa Mbali at the Doris Duke Medical Research Institute, University of Natal, Durban. 21 April 2004.

I – Interviewer (Alain Vandormael)
M – Mbali (Scholar and member of the TAC Durban and University of Durban branch)

I. Would you prefer to see the organisation as a social movement rather than a civil society organisation?

M. Well I'm not really a sociologist so it's all sorts of definitions that one could fiddle with. I think that one of the easiest definitions of civil society is non-profit, non-governmental and with some voluntary commitment in the organisation. That is a John Hopkins definition that is 'bantied' a lot by democracy theorists. Social movements on the other hand are less key in the little sociological literature I've read, which implies a kind of change orientated, organic, oppositional kind focused on social justice and social change. While civil society can include the 'World Timber Federation' and corporate interests there have been civil society organisations which confront the multinational corporations. Civil society can have this very progressive edge to it, but it is also more watered down; social movements have a more radical kind of connotation. I think that the TAC is a social movement because it has been focused on social change and policy change; de-stigmatising the disease has been fundamental, challenging corporate power and challenging government. But I guess it probably tries to juggle and wear different hats in different contexts. For instance, civil society, because it is very mainstream and conservative, might appeal more to donors or governments than social movements. But I think it is more of a social movement because it is based on social change, and you can even argue that social movements are a type of civil society. So I think it involves a dichotomy as well, it's more like the social movements are a subtype of civil society. I think you would say probably say it is both, but it is more within the movement of civil society, i.e. its more of a social movement because its got this radical edge.

I. The media and academics have usually referred to it as civil society. I like the civil society definition because it is very closely linked, and this is what my thesis is talking about, to the notion of democracy. The media and academics have said that the TAC's success in pressuring the government to provide ARVs is actually a victory for civil society and democracy in this country. I've kind of linked it up to the notion of the organisation enabling people to participate in policy issues instead of HIV/AIDS lying in the realm of elites, you know, the ruling elites. Here an organisation has come and taken a policy issue out of the hands of the government and allowed citizens to influence or shape policy rather than it just remaining in the realm of political leaders. So my thesis is sort of heading in the direction, in the way that the TAC is enabling a more democratic culture in our country by enabling people to participate in a policy issue…

M. No, I agree with that but I think that if you said civil society or social movement it is kind of splitting hair – I think it's both. It depends, I think, on the audience as to how it would like to represent itself. I'm not the main spokesperson for TAC; I'm just a representative of a small branch at the University of Kwazulu Natal. Although sometimes I have spoken… the tendency blurs sometimes. Am I speaking as TAC? Am I speaking as a policy analyst? But, usually I speak as an independent policy analyst, then obviously I am biased but…

I. Why would you say the TAC has been so successful? What can you put it down to?

M. I think first of all the constitution is the fundamental issue, because it did enshrine socio-economic rights. The reality of government policy has meant that many of these socio-economic rights have been declined. Now as a social analyst you would say that these rights have been fulfilled with the adoption of a conservative neo-liberal economic policy. You know, in the case of HIV/AIDS with the adoption of a denialist ideology for a number of years, which you could also argue was mainly debated by the corporates in not wanting to divide multinational corporations like the pharmaceutical industry and also not wanting to bend the frugal or physical policies or spending constraints and that sort of thing. And I am not going to go into neo-liberalism, you probably know all about

it – just look at the GEAR policy. But on the one hand, yes, the constitutional court. On the other hand, by the global public opinion, because – you've read my *State of the Nation* article? – like the PMA case, you know, for a while the whole anti-globalisation movement kind of swung behind that campaign to get the pharmaceutical industry to drop the case. And I think from there onwards there was kind of momentum, and I think that when the PMA dropped there case in 2001 it was a huge victory for TAC and for the government. It was always the case when I started working for the TAC that it was a two-headed monster, the problem of why there wasn't treatment access. It was the power of the global pharmaceutical industry and the price monopoly that they had to patent system and the PMA and intellectual property, on the other hand, the government with their whole denialist ideology. [So] first, there was the constitution and [second] the PMA and the momentum created by that, and the unification it left in South Africa and globally behind that issue. The third thing I think is the gay rights element of it, you know, that the TAC has powerful allies in the gay rights movement, AIDS activists as well, like ACT-UP, which has been going for a long time, using militant tactics and full-time lobbying, [being] employed in the congress and facing American politicians everyday. Also Oxfam, a powerful global NGO with lobbying power and full-time lobbying. And I think that really, doggedly pursuing the competition commission. The pharmaceutical industry is kind of in crisis in having backed down on the drug price issue. I mean the Medicine Act now is meant to be law and suddenly they talking about putting out – obviously it isn't a policy thing – but on the other hand basically the monopoly in this country, that's been broken by the TAC and the price of drugs coming down. On the other hand, the victory against the irrational, denialist policy on HIV/AIDS really boils down to taking it down to the streets and having a branch based organisation, building up branches, building up awareness and never losing an opportunity to state the case rationally, clearly in layman's terms to the public through the media. I think also the government dug its own grave really by adopting that position. Like I said in my article, it was never sustainable given the fact that ultimately, you know, TAC had 90% of the public support on the issue once it was explained to the people what the drugs could do and in the election they couldn't afford to have egg on their face around that. Now, we know that there are huge barriers with respect to the roll-out, the government may yet open itself up to more criticism and

then you could say that – you know, when the president said that thing about never having know anyone who died of AIDS, which upset a lot of people. So I mean there still might be huge fights about the actual implementation, like, I think TAC still does have some area of criticism in as much as are enough sites rolling out, is the budget enough, will there be enough provision in terms of demand, and that sort of thing. And, so obviously, there is more room for reduction in drug prices, but basically the way I see it know is that TAC is playing more of a supportive role in encouraging that people are on the drugs adhere and educating communities, fighting stigma.

I. In terms of the relation with the government, it is more of a strategic relation, at times it has been very confrontational and then been very co-operative?

M. Exactly.

I. Can I play devils advocate just for a couple of questions. I know you have characterised the government's position as denialist and irrationalist, in a sense. Let's say I presented to you an argument that in one aspect there position has been characterised like that. But they I've also in a sense tried to – as a sociologist, this is why I am asking the question – they have also tried to address the broader social issues like poverty, other diseases like malaria and TB, and they tried to avoid just limiting the whole crisis in South Africa concerning the disease and poverty to a solution of HIV/AIDS. Now, would you say that it is fair of the government to say that the TAC is basically a single issue organisation, and that the government wont be limited by the organisation's (in their words) 'narrow treatment agenda'?

M. I think that the fact that it's a single-issue organisation has been precisely its strength, actually. A single issue has been easy to unite a diverse range of ideological opinions. And I think its easy, not easy – its been a long struggle – but as opposed to coming from a political party or coming from one religious grouping, you know, it come from a multi-sectoral civil society coalition united on one issue. Because, if it comes from COSATU or Muslim faith or the Catholic church or only gay organisations, then it would not have had

the same kind of strength that comes from a range of different organisations. Up until recently it was just an umbrella body. I mean it is only now taken on more of the characteristics of an NGO having more staff branches, originally it was just a bunch of activists in NGOs and academia all determined around this one particular issue. As for the bread and butter issue, or the whole thing AIDS is caused by poverty or… AIDS is caused by poverty, not caused by poverty, that's the wrong word, it is more complicated than that. There is a relationship between AIDS and poverty, for instance poor people who have AIDS demise quicker than wealthy people who have AIDS. On the other hand, you can argue there is a relationship between AIDS and inequality because poor women often sleep with wealthier men in many communities throughout South Africa. […] But, I think that the idea that AIDS is just caused by poverty or that TAC isn't holistic is loads of hogwash really because TAC has been arguing for along time for extended access to social grants. I think it has really looked at the treatment issue from a holistic point of view, and yes it's a single issue but it is very complicated and detailed single issue. I mean with all kinds of possible drug regiments, the side effects of those drug regiments, there are complicated factors which influence adhering, there are problems with stigma, there's all sorts of things which fall under the umbrella with the question of how, what is the best way to treat people with HIV/AIDS. So I would rather argue that up until recently when the government ran from the issue that it was the government that was being narrowed in its approach to AIDS and was being driven by a narrow ideology which was driven by an obsession with race. The whole idea of some sort of post-colonial plot to kill black people with ARVs, that whole kind of thing that was somehow a plot of the pharmaceutical industry. I mean all that nonsense has been captured in Castro Hlongwane and the speech at Fort Hare. I mean I think it was a narrow ideology on the part of government that was blocking access that I would condemn more than TAC focusing on a single issue. I thing it was a very strategic and clever and a very good way forward.

I. Would you say that perhaps this focusing on ARV treatment and the success of the organisation in basically shaping HIV/AIDS discourse in terms of ARV access, provision and availability… hasn't that in a sense drawn the debate into a sort of a

medical/scientific realm which now leaves the government in a bit of a precarious situation. Isn't the government afraid of allowing the HIV/AIDS issue in this country to become a specific concern of scientific and medical community? Now, on the other hand, we have a group of scientists that are determining HIV/AIDS policy in this country and the politicians don't really have a foot to stand on because they cannot claim to possess this knowledge themselves in which they can compete with scientists in determining HIV policy. So, my question is, hasn't the government's position on this been a kind of 'we will not allow the scientific and medical community' which via the Western channels – well, basically an offshoot of once again like you say a colonialist position – and the government is fighting, trying to resist having HIV/AIDS or a huge issue or crisis in this country being resolved by scientists and the medical community. So is it not concerned…

M. I would argue that the government should always take advise from the experts on any given thing. Like for instance, if we look at how the interest rates are set, should we just pull any old person of the streets and ask them can you fix the interest rates, or decide, ok, we need expertise. You would want someone with an economic degree, with an understanding of central banking, experience with how the interest rates influence the economy, not just any old 'oddbod'. And is an equally if not more serious issue because many people are dying and because for instance in many hospitals in this province 60 % of the paediatric wards are children dying of AIDS in a hideous fashion? Not just children but adults, wards and wards of young adults who are desperately ill, and I think that AIDS isn't just something that should be left to the doctors, obviously there are social aspects, obviously there needs to be access to grants, stigma and discrimination issues, obviously traditional healers, inter-group collaborations with doctors in other sectors – so it needs a multisectoral approach and it needs an interdisciplinary approach. I don't think there is anything wrong on purely scientific questions bowing to accepted expertise, I mean I think that's what happened with this roll-out is that TAC through the media and all the strategies that I suggested has actually forced the government politically to bow to the best medical and scientific knowledge.

I. There was an article that appeared in the Citizen, and it was related to research that was done by the Afrobarometer, and they said that most blacks in the country agreed with the president's views on HIV/AIDS.

M. Well, that's quite interesting, I don't know about that. I mean first as I said, from a qualitative social sciences is, how deep do surveys really delve into society and culture…

I. But let's say you do not question the research methods, you do not question the outcome of the data and you just try to comment on… if it really was the case. More than half, or a substantial number agreed with the presidents views, what would your comment be?

M. That actually wouldn't surprise me, because in my MA I argue that the question of AIDS stigma, attitudes towards AIDS which early AIDS activists were encountering in communities throughout South Africa in the 1990's, and many people saw it as a white disease that was being blamed on Africans as part of racist plots. Similarly the whole argument was common that AIDS is a bread and butter issue wasn't really a physical disease there was a great deal of stigma about, also racialised stigma. And the notions that it was an American or Afrikaner plot to discourage sex, basically to limit black sexuality. So that wasn't surprising. On the other hand if you delve deeper, if you cut deeper into the long term ethnographic field work, or focus groups, or in-depth analyses and you approached it form another angle, perhaps not using such medicalised terms, it would say something along the lines there are lots of young people dying these days, notice how they are burying people three times a week, etc. Perhaps people would describe AIDS in other terms and see it as a real problem. I gave a seminar on traditional healing and one could believe for instance that a curse has been placed, or there were maligned spiritual forces arranged against oneself due to the negative and malicious witchcraft acts of someone else. So if you believe HIV causes AIDS, but also that it is their ancestor's displeasure that is at the actual heart of the matter, that's the ultimate core – just like people can believe in God, like Christians believe in God and that medical science simultaneously works. So I think it would very much depend on how the question

was actually framed. And then the other thing is that people don't have very high levels of scientific education, I mean even middle class whites and Indian people, when I sat at stalls on campus, particularly at the height of the denialism, and people with AIDS don't exist, I used to get that every day – but the level of scientific education is woeful beyond belief. What does the average person poor, rich or otherwise understand about the virus, especially not a retrovirus that mutates and then how that actually decimates the immune system and how actually retrovirals can prevent all of that, you know, the decimations from happening. So if people say they agree with him, it might be more to the point of do they actually understand – which is not to be patronising, I'm not trying to say that any one group of people – but I do generally think outside academia I don't think doctors did a good enough job of actually speaking to the general public and actually breaking down the mechanisms to your average person. It has been my finding at 'med' school that a lot of presentations by doctors on AIDS are so technical, I mean I can show you some stuff, the actual tiny gene coding, the exact formulas, I mean there is a lot of detail that you can go into that is just mind boggling. And I think it is difficult often for them that they find that detail so fascinating, it is difficult for them to break it down for the average person in the streets. So I think a lot of people genuinely were confused, and also if you are faced with a natural crisis, if you're faced with the potential of half your 15 year olds dying, of course the temptation to say it cant be true, or if you regularly have unprotected sex and you have had multiple partners and you suspect you might have HIV it's a very tempting idea to think it doesn't exist, it's a plot let me carry on as before. I don't have wrong behaviour, I don't have to be caring and nice towards people with HIV, I don't have to be involved in a critical social movement, I don't have to get – you know what I mean, I can carry on as usual and pretend that all people dying of AIDS is just an opportunistic infection, there's nothing strange about the fact that 20 and 30 year olds dying. I think on a psychological level, that you might find appealing, is that if something bad happens to you, if you hear you going to die if you're HIV positive, or you hear you're going to die in 6 months time – it is easier to believe that it is just not true, it is not happening to you, block it out. I think the ANC's overwhelming election was partly due to the fact – I think the results could have been a few percentage points worse – if they hadn't rolled out.

I. Should the TAC become the voice piece of the scientific and medical community in the sense of popularising the technical jargon, so to speak, of doctors…

M. I think that you need to look at doctors that went through organisations like the South African Medical Association, the South African Medical and Dental Council, and then there is all the medical schools which kind of represent their interests (hospital companies), I think that the upper middle class, very powerful medical society, in as much as popularising goes, yes, I think that is definite, it is a must…

I. …to become the voice piece of a scientific and medical ideology…

M. Not… I think ideology is a bit strong. I think that informing the general public about what steps they need to take treatment successfully, to prevent an early death and prevent themselves from becoming HIV- positive. I think those facts that patients and their families know, I don't think you need to go into detail. I think it just needs to be, you need to take 3 tablets because… otherwise you will get sick again, you need to take them twice a day, at the same time every day, etc, just the basic. For example in Diabetes they don't go into all the mechanisms around insulin and … Diabetics, the main thing that they and their families need to know that they are chronically ill, they need to change their lifestyle. So I think TAC – breaking down the stigma, telling people 'look, you know, it is illegal to sleep with people if you have HIV/AIDS, and also to suspect that you have HIV you have got to come forward and for a test', because otherwise, you know, many people are to scared to get tested and leave it till the 12th hour, till they've lost so much weight and they're so ill. It is far better if you can test earlier and preserve their health and begin treatment in a timely fashion.

I. Last question, you say…

M. …I think TAC should remain as it is, a representative of ordinary South Africans, an umbrella organisation that shares human rights values and a commitment to public health. And most importantly I think they will need for a long time to come to be a critical voice

that people living with HIV/AIDS in the communities they come from, and I would rather see TAC remain that kind of critical PWA voice – because NAPWA, I mean, it just ended up becoming a government mouth piece, and now there's questions about its finances and a lot of people with AIDS that I know haven't been happy that NAPWA didn't properly align itself with TAC, and I'm sure you've read about that conflict…

I. Last question, also controversial, you say HIV/AIDS is highly politicised but I'm thinking of arguing that the situation is going to become in a couple of months or years highly de-politicised in terms that people will no longer be able to play a part or shape the decisions that become made around HIV/AIDS because the whole policy issue has now become removed. Apart from it lying now, it was lying in the hands of politicians, now it lies in the hands of scientists, doctors and medical practitioners, how do citizens, ordinary people become engaged and how can they further influence the way HIV/AIDS policy becomes determined? Because now there is just a two-way transaction between a group of elites, while once again ordinary citizens remain excluded from this process. Do you understand the point I'm trying to make? Once again the whole issue is being reduced to a technical capacity, we just need to find anti-retroviral drugs, we just need to sort out problems of how we are going to distribute it, what tablets need to be taken, but at the end of the day the larger social issues remain un-addressed, so to speak. I think that poverty, when Mbeki was talking about poverty, in all of this there was now a movement to place attention on poverty because poverty was highly linked to AIDS. Now what's going to happen is that AIDS just becomes associated with antiretroviral treatment, and once again the social issues like poverty, gender inequality now become sidelined, in this whole attempt to resolve technical logistics of the ARV rollout program.

M. I don't know if that is going to happen. I think TAC is probably going to shrink back to its original size, to your real hardcore activists. But I don't think that's a bad thing, but I think that if we all carry on monitoring – I think there are going to be hiccups, I mean look at for instance the whole issue extending the child support grant. Now we find an activist, a social grant lobbying group pushing very hard to have that extended beyond the age of 6. The problem is the grant being unevenly implemented across provinces, not

enough children are getting it; poverty remains an issue for children. So now they are taking government to court about it. So these things never… poverty takes a long time to get right and there can always be more hiccups, I would expect more hiccups actually. On the other hand, as far as poverty goes I think TAC should form links with other NGO's like Black Sash, Access and Basic Income grants and work congruously on social grant issues. And also I would argue potentially… look it could slit as well because there is always a more left wing or political wing of TAC, some people have more of a head in anti-privatisation forum, or a social forum, so I think there might be some splits. I think what is going to happen is that a lot of people who join TAC were politicised previously in other ways, gay rights, left wing activists, or trade unions, and I think most of the people melt back in to other political homes. So I think some sort of coalition will remain and I think it can be easily resurrected at any given point as required. So also I think poverty is necessarily an issue that relates to the rollout because people who haven't eaten will probably just vomit up the drugs if they are malnourished. So it is going to have to be addressed the issue of social grants and, you know, nutrition. And I think it will force the government to put its money where its mouth is about AIDS being so strongly linked to poverty. So that's a future battle around basic income grants… We will have to see what happens…

2. Interview with Annie Devenish at the University of Natal. 22 April 2004.

I – Interviewer (Alain Vandormael)
D – Devenish (TAC member of University of Durban branch and former TAC branch co-ordinator)

D. […] Because our government does not have experience they are not really good at taking criticism, and they tend to become very defensive, and I think that kind of comment – of TAC sort of being a one issue campaign – it comes from […] But I do feel that the TAC has really focused, its primary focus, has been around the HIV/AIDS issue. And so it has kind of used AIDS as a route into looking at the whole public health system. I mean in a way where that kind of comment comes from because it is – when

you think about it –quite problematic for government to be linked to one social movement, and where does it stand in regard to the others, or if there is a standard of fairness in terms of kind of engaging civil society, it can't favour certain organisations over others. But, at the same time, the thing is providing proper health care to people with HIV/AIDS, providing ARVs to people with HIV/AIDS, providing ARVs to treatment of opportunistic infections to prevent mother to child transmission – those are things that the state should be doing. So you know, the TAC is perfectly right, those are things the state should be doing anyway.

I. I think Thabo Mbeki made a mistake. I think he underestimated the power of going against science. He chose to take an issue which should have belonged in the scientific realm or medical realm, and he tried to politicise it in a way. And this is what Mandisa [Mbali] talks about, is how the government's position in many respects has been an ideological one in terms of resisting the old colonial force of science or this western notion…

D. …this idea of diseased African bodies….

I. …and I think he made a mistake because he underestimated the power of going against science since it is always backed up by firm evidence so to speak, or experimentation or proof. What do you think about Mbeki's position, I know Mandisa thinks it is a denialist position but in the same vein do you think there is a reason for him going against the normal HIV/AIDS perspective?

D. Yes, I think Mbeki is a real sort of intellectual and I think that I tend to agree with Mandisa's ideas about it. Not necessarily about the denialism, but about this idea that he wanted to reject this notion of African bodies as being diseased, kind of imposing a very Western perspective on AIDS. Everyone in Africa has AIDS and they are all going to die because of people just having sex all the time. So this idea of somehow African sexuality being pathological and African bodies being diseased comes from a very intellectual position where he has obviously engaged with the main kind of theoretical writing on

that. I think another thing he was trying to do was to say we can't necessarily afford these Western solutions, we don't know whether this is the best thing ideal to the African renaissance, we want to try and find an African solution and I think this also influenced his thinking. But I think also what happened was that he made a mistake and he was too proud to go back. And I think it seems… Manto, she is such a proud, she is so arrogant – pride isn't the right word – she is arrogant, more so than Thabo Mbeki. I think she was not prepared to admit that she was wrong. Now we are going to have the rollout, seeing ARVs as just not being economically practical or our health system just not having the structure, that you have to administer ARVs in quite a controlled environment and it is quite complicated, you have to take the medicine at the same time everyday, you can't miss out, you have to have a lot of counselling before and during, you need a treatment partner. And I think there were quite legitimate concerns from government that they just couldn't provide that sort of service and that it would be dangerous to try and rollout if you didn't have that kind of thing.

I. Has the TAC focused on those aspects? Have they understood the government in those terms? In a way the organisation has just been about let's get the drugs out first and then we can…

D. No, I think, that hasn't actually been. I think TAC has always been that we need to get the drugs out as quickly as possible, that we need to educate people, so the TAC has a very strong kind of treatment literacy element in it, and at the moment they are busy training people, and they have been for a number of years. So it isn't just about that we need drugs, it is also about the government who needs to educate people, and we are also doing that. If necessary, we will show the government how you can do it, about treatment literacy, educating people about when to take their drugs, that they must take them every day. Another kind of key element within treatment literacy is educating people to make sure they have access to information so that they know their rights, so they can then use that information and kind of almost say to the government that it's our right to have treatment. We know that it can be done, this case study has shown that it can be done and that kind of thing.

I. Will that be the role of, in a way, couldn't one argue that the success of the TAC may end up diminishing the importance of the organisation itself. Because it was built up in terms of getting the government to supply ARVs, now that the government is supplying ARVs is it going to remain as prominent?

D. Well I think the TAC's strategies have changed slightly. It has moved from being a focus on the access to treatment to do treatment literacy. The TAC is trying to build itself up to play an important role in monitoring the rollout. So I think it has managed to evolve its position and its strategies accordingly in a very clever way. I mean recently there has been a focus on the TAC a lot more towards empowering communities and that fits in with this whole thing of preparing people for the rollout. So I think that even once the government implements an ARV program and its running there will still be an important role for TAC in educating people and monitoring and perhaps advising the government.

I. Do you see the organisation moving to broader social issues or social aspects that may not specifically rely on treatment or treatment literacy?

D. I suppose it could happen, at the moment I feel the whole issue of treatment literacy and monitoring are still huge issues that could take a long time to deal with. But certainly, the TAC has always acknowledged the sort of social and political and economic and cultural context, in which AIDS is situated. Possibly what is starting to happen is that you will find that women aren't adhering to treatment because of domestic violence, and this is coming up again and again. I think TAC could kind of branch into something like that, into other areas that are perhaps affecting treatment literacy and monitoring the implementation.

I. I've got another question, and this is a bit of a tricky question. It's a very abstract question so I don't know if you will be able to answer it. I've kind of got this idea of the TAC as, in many respects, defending or affirming the status quo of HIV/AIDS in South Africa. In terms that the best way to solve this problem is through a scientific and

medical intervention program. That HIV/AIDS is an enormous problem in South Africa, in that respect the TAC have been very confrontational with Thabo Mbeki. When, for example, he said AIDS is not the number one big killer in Africa, and then he brings out 1995 statistics to show of ten years ago to make his point – saying poverty is the cause of AIDS, not the sexual patterns of black people, so to speak. And [the TAC is] even [confrontational with] people: I don't know if you read Riaan Malan's article in the Noseweek when he said that HIV/AIDS statistics is highly overestimated, the deaths and the mortality rates in South Africa are far above what they should be. The TAC's Nathan Geffen wrote two articles refuting the evidence he provided. It seems like the organisation is not only concerned with providing ARV treatment but also defending the scientific orthodoxy or the position on HIV/AIDS from these factions which seek to reduce its implications for society.

D. I think the TAC has used scientific evidence, or tried to use it very powerfully to make the argument that HIV causes AIDS and then also to say that within the scientific realm you can find the most effective treatment. I have not had much of a chance to speak at national level about it. I know Zachie Achmat is interested in traditional healers and alternative medicine, so I think TAC certainly acknowledges HIV/AIDS goes beyond the scientific, the sort of physical body, and is affected by peoples social context, by their economic contexts, and I mean TAC supports the basic income grant very strongly. So they do, I think within the organisation there is a connection between… [Interruption] Where were we?

I. We were talking about social grants, what does that entail exactly, what is the TAC doing with regards to that?

D. Well the TAC I think has contact with the Basic Income Grant Coalition, I know the TAC does also have contact with other social movements around other issues. I sit on the Kwazulu-Natal provincial executive committee which is just an advisory body to the kind of provincial office. At our meeting normally we have somebody from the Children's Rights Centre, and we have another NGO. So there is a sense of networking and contact,

I can't say to what extent it exists. Certainly, although HIV/AIDS and health issues are the primary focus because you can't do everything. And I think perhaps that the TAC wouldn't be successful if it tried to take on too many different things. I think part of its success lies in the fact that it has focused on and put all its kind of energy in resources into specific issues.

I. A lot of people who are focusing on democracy say that the TAC has used the constitution, and that they've enabled the government to change its position on a sort of controversial policy issue. My argument is that one of the successes of the TAC is that they have enabled citizens to participate in a key political issue, namely HIV/AIDS. Instead of the government just deciding how the policy becomes framed now an organisation like the TAC has actually allowed people to speak through them and voice their concerns, or voice their opinions on the matter. In that the respect the TAC has enabled this culture of democracy to develop because you don't just have a ruling elite determining policy, now you have from below the shaping of this and that policy. I don't know what your thinking on that might be?

D. Yes, it's a very exciting idea and I do agree with you that TAC has provided a platform for kind of ordinary people to speak out and get there opinions, and TAC has certainly sent submissions to the government with regard to its different policies. In terms of drafting of the new policy TAC often sent some kind of submission saying we think you should include this, this and that. It is more complicated than that though. In Kwazulu-Natal, from my own experience working with people in the provincial office and being a branch co-ordinater I used to represent our University branch at meetings where there would be people from all the other branches. And certainly, what I found very interesting is that in every meeting there is a very strong sense or democracy in that there are a lot of those who speak and everybody gets a chance to speak, at that level I find it very interesting. Even though it means that meetings will go on for 5 hours sometimes – which tends to be irritating – but at the same time I know that there is a place for that and that people are getting a chance to speak and able to speak there minds and that kind of thing. At the same time there are still lots of problems within branches in

Mandeni and maybe Stanger, I think there are lots of members of TAC in the ordinary branches who still have a very limited understanding of the issues, and who aren't always – I mean TAC hasn't been able to capacitate all its members. I don't know if Kwazulu-Natal is different, I know that the staff have been under-resourced and they have a limited scope, although they are trying their best. But there is still within our province, certainly among ordinary branches, there needs to be a lot of capacity building still to allow people, to allow ordinary members of the branch to kind of engage more actively, but you can't expect that kind of thing to happen overnight. It is complicated but you do have this very democratic culture in meetings which I find really interesting, where everyone is allowed to speak and it is done in a very democratic way, and peoples' opinions are asked for and peoples' viewpoints are sought, and I think that's very, very important.

I. Two concerns of mine, and these are basically the two final questions. One concern is that the HIV/AIDS discourse in this country has been pushed or shaped into the form of – it has been basically determined by the outlook of science and medicine. In a way if people try to raise other issues that may not necessarily be scientific or medically orientated there is an immediate backlash from the TAC with regard to this, which is why I was asking the earlier question as to what is the relationship between the organisation and science. My concern is that where previously the government decided how policy becomes determined therefore excluding citizens and members from civil society – don't you think in the way as soon as science takes over, as soon it becomes medicalised that once again ordinary citizens become excluded from the policy making process because they do not posses the scientific or medical knowledge, they do not possess the capacity to question science. This is all based on the assumption that science and medicine is not God itself, you can actually question some of its postulates every now and again. Isn't the success of the TAC forcing HIV/AIDS discourse in this direction once again going to exclude citizens from the policy making process?

D. I mean it is certainly true that TAC does tend to situate AIDS in quite a scientific paradigm, it uses science to reinforce its own arguments, its own positions – that HIV causes AIDS, that there are effective treatments out there. But I don't think the TAC sees

HIV/AIDS as exclusively as a biomedical issue. I think it is also concerned… Before that I wanted to say, another kind focus of TAC is actually people in the kind of medical scientific discourse, the idea is to empower ordinary people to understand and to be able to understand the scientific discourse around AIDS and to be able to use it, to actually argue for treatment. So, yes, TAC does focus very much on a scientific paradigm but it is also trying to empower people to understand science, to understand medicine so that they can use that. At the same time the TAC does acknowledge that HIV/AIDS is around broader issues… and that comes out through TAC contacts and other NGOs that deal with other social and economic issues.

I. The reason why I ask is because I actually work as a researcher on a funded program and we are trying to form intervention programs for mothers who give birth who are HIV-positive. We had a focus group session the other day with a number of people, one of them was also a traditional healer. There was two focus groups, one was with regards to finding out people's perceptions of the government placing its attention on HIV/AIDS, and what seem to have come out of those sessions was that the government is placing too much attention on HIV/AIDS in the sense that now they are not paying enough attention to other aspects, like TB and cancer, for example. The reason I'm asking this is because an article appeared in the citizen about two or three weeks reviewing data collected by the Afrobarometer, which is quite an important journal. After a year of research the article came out and said that most blacks support Mbeki's views on HIV/AIDS. And I'm beginning to wonder if there seems to be two sides to this argument. One, what people are saying on a ground level about HIV/AIDS, and two, what other organisations and the medical community are saying about HIV/AIDS. One is trying to force the debate in a certain direction and the other group – backs and people on the street – are actually within agreement with what Mbeki is saying about HIV/AIDS.

D. When you say, I mean Mbeki said a number of different things at different stages.

I. I still got that article from the Afrobarometer, but this is something that took me by surprise because you would of thought that Mbeki was standing alone on this issue. And

when you actually do research on a ground level when you ask people what do you think of this they actually are in agreement.

D. Well, certainly, I mean I have read a newspaper articles and that kind of thing at research that looked at peoples primary concerns, and HIV/AIDS isn't top of the list, it is somewhere near the top but its normally unemployment that's normally the biggest concern. I think perhaps there are people who do support Mbeki in thinking that AIDS is not so important but that could possibly be linked – I mean there are still enormous kinds of issues of denial within the population. Incredible questions of stigma, people are just dying and there is no knowledge of it – that they actually die of AIDS. So you have to take that into consideration this question of denialism amongst ordinary people and linked to huge questions of stigma. I have heard lots of stories of people being completely ostracised, kicked out of their houses, you know, completely abandoned by their families if they disclose. So, I mean that's another focus of the TAC is also to try break down the incredible stigma around HIV/AIDS because a lot of people still haven't been tested. The TAC does also focus on voluntary counselling, and that's part of treatment literacy.

I. Mandisa said, when I asked her that question yesterday, that it is actually easier for people to agree with the president, it's so much easier to say well the thing doesn't exist. Her argument was that people are still not informed of the scientific and medical aspects of the virus; they are still kind of trapped in this traditional outlook on HIV/AIDS. So she was saying it could relate to stigma and denialism as well. I think it's quite interesting if you can relate that to what's being said on the political level and how that's filtering down…

D. Well it does make it so much easier if you want to deny it, and then you have the president denying it, it kind of reaffirms, it makes it so much easier for you to do it. The question of why HIV/AIDS has been stigmatised in the way it has in South Africa, and not say other sexually transmitted diseases, is very, very interesting.

3. Interview with Sifiso Nkala and Cindy at TAC Branch, Durban. 22 April 2004.

I – Interviewer (Alain Vandormael)

N – Sifiso Nkala (Provincial organiser)

C – Cindy (Provincial co-ordinator)

I. In the last year since I've been writing my thesis I've always called the TAC a civil society organisation and everyone says 'no, no, it's a social movement'. When I ask if it is a civil society organisation everyone gives me a different answer, so perhaps you can give me your own opinions as to whether you think you are a civil society organisation or a social movement?

N. Actually civil society, the TAC was formed by civil society and civil society deals with social issues, I believe it is one and the same thing. It's something that keeps on going, as a social movement it is the same thing.

C. I would also go mainly with the word social movement.

I. Why do you think the TAC has been a good thing for democracy? When the TAC forced the government to provide ARVs, the academics and the media said it was a victory for civil society and democracy. Why do you think that would be? Do you agree with them, disagree with them, why do you think the TAC is a good thing for democracy? What has it done to invigorate democracy in this country?

C. I mean we are exercising our rights; we are campaigning for the access to treatment mainly because everyone within our constitution has a right to life, to be treated with dignity and people living with HIV died in an undignified way and they died unnecessarily – deaths that could have been avoided. If our government had the political will they could have made a difference and that is what we are pushing for. So if people say it is a victory for civil society, yes, because the impact of HIV was on the society. It was the poor people who could not afford to treat the disease, the public sector which is

run by the government […] So, yes, it is a victory for civil society, unless my colleague has anything to add to that.

N. Yes, I would like to add that the TAC is defending democracy. We do appreciate that we have democracy, it has been 10 years now and we must make sure we defend it? It is only civil society organisations which can be able to defend it.

I. Because in a way everyone says that the TAC has used the constitution and the right to public health care and public access, and the government has been preventing this. And one also says that the TAC has used the constitution, which is the cornerstone of our democracy, to oblige the government. But I'm also saying that the TAC – I don't know if you will agree with me –has allowed ordinary people to influence government's policy. Instead of the government saying 'this is the HIV/AIDS policy' the TAC has allowed people to express their views and to say 'no, we do not agree with you.' And, it is more democratic in that way that people can participate in the policy making process.

C. We agree with you on that…

N. Because most of the issues are discussed with the people at a ground level, we do have branches, where we let people talk, and we only create guidelines. But we understand that it is from a down-to-top approach? That ensuring our position is doing administrative work, giving guidelines.

I. So you normally have consultation with people on the ground?

C. We do have branch meetings, district meetings, inviting other NGOs, and other participants of the public.

I. I'm going to be controversial now and I would like to know what you think about the government when they say that the TAC is a 'single issue' organisation and that the

government doesn't want to be limited by – this is their words – 'the narrow treatment agenda' of the TAC. What are your thoughts on the government?

N. If I could comment on that, I would say that most of the diseases are linked to HIV, for instance it is easier for you to catch TB if you have AIDS, or rather, if you are HIV positive. It is easy for you to catch pneumonia if you are HIV positive, it is easier for you to catch most of the diseases if you are HIV positive. Then, if you do ensure that you treat HIV it is going to be easier to treat the other diseases because you need everyone to be involved in this HIV committee. We [TAC] will ensure that most people do not get compromised with other diseases through their compromised immune system. And I believe it is unfair that we only focus on one disease and ensuring that other diseases don't get attention but everything does get touched with this.

C. The way I'm looking at it, your question could be two ways: first, it could mean that the TAC is only focusing on treatment mainly ARVs or it could be meaning treatment as a whole, for whatever disease; or, it could mean, only focusing on treatment and not other issues like prevention. It could mean both of those. But on the issue of focusing on treatment as in ARVs this is not true. All you need to do is look at the history of TAC. Our first campaign was the treatment for opportunistic infections, and the only reason that it seems like we've only been campaigning for ARVs is because the government has had a strategic planning which was not done properly. It did have a prevention program and it does – it had just before last week – also have a PMTC program, it has a PP program, it has a program of opportunistic infections but it was still lacking the highly active ARV program which is very essential in order for people with HIV/AIDS to survive. So yes, the focus has been on ARVs but not in the only thing that is needed but in addition to a plan that is full of all the things that is necessary to keep an HIV positive person alive. The TAC has also included employment of new doctors, laboratory machines and everything. So it was a treatment plan at the end, it was a full plan which covered every area. So it would be fair to say that we are focusing on HIV. If they were meaning that we focusing on treatment only and they are combining all of things I would say again it is not fair because there are many organisations that are dealing in prevention

and government has played a huge role in supporting those organisations and has done very little in terms of treatment issues. With the drug companies, they have been dragging their feet. The Minister of Trade and Industry could have done something to ensure that we have compulsory licenses or do parallel importation but there was not enough political will to motivate and actually implement it. So on the treatment side, the government has been lacking but with the prevention, yes, it has been good. So there just needs to be a movement that needs to put pressure, that needs to emphasise that it is just as important as any other HIV program. If you also look at our organisation we have many networks, and it's not only treatment related networks. We network with the Law project, at the moment we are currently with Lovelife and mainly other organisations that are within the HIV field. So yes, that is what I would say.

N. And one other thing is that they said we are even taking the money from the diabetic, you know and stuff like that. Thats what I also wanted to say, there is no organisation that has lobbied for cheaper diabetic treatment and stuff like that. There should be people, or either companies should take a stand on that, you know? They are very costly, the medication for diabetics. But HIV does cost life, you know, and people get infected lead on to other diseases – you understand that. Then if we do fight HIV we can ensure that other diseases also are getting proper attention, you know, as I spoke of TB and pneumonia and other stuff…

I. In the past Mbeki has said that poverty is the main social factor in the prevalence of HIV/AIDS. His argument seems to be that if you address poverty and social issues that go with poverty, HIV/AIDS will become more manageable and might even diminish. What do you think about his views on poverty rather being the cause of AIDS than the other way round?

C. To a certain extent you would agree with him but I mean that is like an open-ended statement. You could put in so many things and you could interpret the statement in so many different ways. So it is an open-ended question – I mean statement – which is

difficult to answer with a straightforward answer. You have to look into a number of issues in order to address that statement.

N. At one other end I do agree, I do understand. I might ask why so many professionals are HIV positive, health professionals. I might ask also why so many teachers are HIV positive. Is that because of poverty? Poverty does serve its own limitation in HIV. So we need to address it holistically. That why some other times, or most of the time I don't agree with our president. In one statement he said he never saw anyone who is HIV positive. He doesn't know anyone who died of HIV. That leaves the public with confusion – I don't like it. I do trust the president but the problem is the approach that he is talking…

I. As TAC members why do you think Mbeki has taken this position? What do you make of it? Why is he being, in Mbali's words, irrational about the whole…

N. Ok, personally, this is the political will. In the TAC we don't believe in the class system. And I believe that Mbeki does believe in that class structure, I don't actually believe in it. That's the reason why: because he doesn't have that political will to providing treatment. Firstly, it was with the pregnant women with HIV. It was the TAC which fought for MTCTP. Secondly, on the difrucan campaign, the TAC fought for that. Thirdly, we negotiated a treatment and prevention plan, the government was not prepared to do that. The people who had money afforded that medication. This medication is also available from those big countries, those greatest countries, even Botswana does provide such treatment – but in South Africa we want to provide such treatment. He is aware of that, and thus it is the lack of political will.

I. I'm just trying to go a little deeper. Why? Why has he taken this position, why did he take his own particular views, why did he question the causation between HIV and AIDS, why did he talk to dissident scientists, why does he say things like he has never seen anyone who has died of AIDS, why does he say AZT is toxic? Why does he take these views? Is he trying to forge a new African renaissance? Ms Mbali says it is something to

do with a racist or racial discourse, that the scientific establishment is trying to impose itself on African People, this idea of Africans who are sexually promiscuous, who are engaging in sexual deviant behaviour. Mbeki is actually trying to oppose or resist these kinds of ideas about black people and HIV/AIDS. Do you see any kind of ideology behind Mbeki's decision to question HIV/AIDS, or to deny the importance of HIV/AIDS in South Africa?

N. My understanding is that Mbeki is an economist, you know. He learnt at an international university, you have got to understand that he is forming an ideology. These… linking with the dissidents, not believing in HIV, is costing people. I might not know the reason behind it but you have got to ensure that you understand that this involves peoples' lives. Instead of just formulating a theory from nowhere which doesn't have any basis. Because if you've never met someone who is HIV positive whilst we've got so many in hospices, we've got so much in hospitals, we've got so much living at home, everyone does know someone who is HIV positive within his own area. If he wants to prove that this person is HIV, he could have visited someone or either spoken to some of the doctors, testing someone and seeing the results and stuff like that. But to formulate such a theory at the expense of the people. People die daily and the economy will also go down; South Africa will be in big trouble if they don't solve the problem at the earlier stage.

C. I wouldn't want to appear that I'm involving the organisation about Mbeki's decision to treat HIV the way he does, but it could only be personal ideas why we think he is like that. Because if you look at the history of TAC, as much as it has taken a long period to get to where we are, the information they [government] have been hiding has been more them running away from those current circumstances rather than telling the actual facts of why they are doing what they are doing. For instance they would say 'that the drugs are toxic', 'I've never seen somebody who is HIV positive', 'it is poverty'; but you [should] know to tell people exactly what they think or what they are trying to prevent, it's something that has never been said. You see it becomes difficult to actually ask that

question I think. It is easier to make your own personal view from what you have seen rather than making statements from something…

I. Mbeki never said 'I believe in this and this and this.' I think he underestimated the power of science and the medical perspective of HIV/AIDS. He attempted to challenge it, he made a mistake, and I don't think he realised his mistake, or he didn't realise the negative sentiment that was coming from this question about HIV/AIDS.

N. One other thing, I used to think of the economic perspective, because you understand that economists never agree most of the time? And they do always have their way of thinking whenever they think about the economy of the country than thinking about the risks to be taken. But when I try to analyse his [Mbeki] way of thinking I don't get to understand why is that: is he thinking about the future of the country, or is he thinking about now, the short term, the short term goals? Because there are short term goals, medium term goals and the long term goals of the country. And looking at what kind of people will be living by the time – let me talk about 2010, 2015 – how much people shall be infected, how many people will be dead by then if I don't provide ARVs. In an economic perspective, how many people shall be absent by the time because you have got to ensure that you think about the ability for people to perform – can I perform at work?

C. Another thing too – when you look at this whole HIV/AIDS issue – Mbeki wasn't really looking at HIV as something within human beings. It was more of human beings as items or projects or products. For instance – this is my personal view of what I think now – maybe this is what they looked at: Ok, we need to allocate this much budget for this and that, and they looked at different issues. When you look at HIV, a person who is HIV positive goes through four stages, which are 1,2,3,4. To treat somebody who is in stage 1 it costs, let us say, 10c. By the time they reach stage 4 it may have tripled or been multiplied by 5 or 4. Today, maybe when they were setting the budget they said, 'ok we are allocating this much money for people in stage 1 and this much money for people in stage 2 and for the people in stage 3 who have many opportunistic infections and costs a

lot but at least they are still productive in this country, they can go to work and bring back the money that we are going to invest in them.' When he looks at people in stage 4 he was thinking there is maybe like (this is what people are complaining about) that people can't adhere to TB how can you expect them to adhere to ARVs? Maybe this is what they were thinking: Ok, if we put ARVs and these people who don't adhere to this medicines what is going to happen to them? Are we going to get back this money by these people who are being productive and contributing to the economy? Maybe the decision they took is that 'no, they won't take all these medicines, it is not worth it.' That's the idea that I have when we are sitting around the round table and discussing issues…

I. That's a very interesting point you make…

N. And one other thing is that I won't say it is the ANC, it's just people – because we might understand the Ruth Bengue disclosed that one of her children is HIV positive – we know people that are in the parliament that are using ARVs, within the ANC. One other thing: Dr. Zwelinke applied for the global fund, you know, and involved ARVs in that global fund, the application, and it was approved. Then I won't say particularly, it is the ANC, it is just individuals within the ANC who have control.

I. Like the Health Minister, the two most important people.

C. Thabo Mbeki, and the Trade and Industry Minister.

I. Alec Irwin.

I. Two weeks ago I read an article in the Citizen. They were reviewing an article that appeared in the Afrobarometer, which is quite an important journal. They did research for a year and they found that most black people in South Africa actually agreed with Thabo Mbeki on HIV/AIDS. What do you make of that?

N. You know, we have got to understand that ANC is having a tripartite alliance, publicly we don't have to fight with him. Because you do understand that it's more than two-thirds majority that voted ANC, and even before people were enjoying being with ANC due to political history and stuff like that. Then, we have to understand that people who are taking part in the struggle, or rather a democracy, belonging to the ANC they are obligated to defend your president, obligated to defend whomever, because that is the resolution that was taken in the National Executive committee. That was taken by your president? Because you have got to ensure that you are secure or whatever, even though you don't support that decision, but you are forced to defend it and promote it. You have got to ask yourself how TAC got to mobilise so much people in marches. We do share the same constituency with the ANC, we do share the same constituency with COSATU? We work with COSATU closely, which forms part of our National Executive Committee. Locally we were discussing with COSATU yesterday and they do form, they do share the same things, but when it comes to speaking with the journalists they need to defend it.

C. And just to add to what Sifiso has said, TAC is an organisation and it is growing, which means as much as it reaches so many areas but there are still so many areas that we need to go to. And some people still don't have information around treatment issues. They don't understand what the difference is between somebody with HIV, the stages one has to go through, the treatment that is available, how to actually manage the disease. People are not aware that what they see is somebody that is positive and that they are going to bury, because those people are scared of stigma, it is still early, still fresh and healthy. They come when they are sick and they want to get better and you find that because they don't have information they don't know how to get better, they sit and die. So when they think of HIV, it's the disease, death and burial. So the suggestions that Mbeki had… obviously if you didn't know about treatment and you didn't know about how to manage HIV you would also think that prevention is better than cure. But you will also think that you will only have one focus of prevention awareness and positive living because that is what you know. You only have one view, only have one eye, but if you have another eye you would take this plus this makes one whole person. So that could also contribute to more people agreeing with him.

I. So you would say it's because of this political patronage or political bond with the leading party of the ANC and the president, and you would say on the other hand that it is because they are uninformed, and that they are not properly informed about all the HIV/AIDS issues?

N. COSATU has had so many strikes within this ANC government, SACP has had so much differences with the ANC but they wont go public and undermine ANC government? Even though there are such things they are always saying vote ANC. We will not say Thabo Mbeki is not fit enough for ruling the country? We will say he is doing his best but he has some limitations, that is all that we can say. We have got to, it's just an obligation because it's an alliance, we have signed in 1921, the SACP was formed in 1921, and in the 1955 this freedom charter was made and stuff like that. They formed these armed struggles, they disbanded this arm struggle in 1990 and stuff like that, we have got a history together.

I. What is the role of the TAC now that it has successfully campaigned to pressure government into implementing a treatment plan?

N. Actually, yesterday I was in one of the hospitals we are supporting, we are not monitoring ARVs but we've got our own role to play to ensure that this becomes a success, a reality. We will not stand aside and say that we are audience or that we are monitoring, You know, we should assist, we should lend a hand. Forming support groups, ensuring that people get literate about treatment itself. How to get adhered to the medication and how to ensure that other community structures play a role for everyone else, and within the hospital itself we have got to be involved in many of the structures of society.

C. Another thing that you need to look at – the rollout. In the first year every district will rollout, but it will only be in a period of 5 years. Every local clinic will have ARVs available which means we need to do what Sifiso is saying. We need to support the ARV

program and out strong point is community organisation. We will continue to assist at the hospitals and provide a treatment formulation, and we will go to the community to support groups, other NGOs, continue to pass on the message that one day everyone can easily access [treatment]. Everyone is able to benefit when they need medicines or whatever medication they need at that point, that everyone is completely aware that one day you could sit at home and talk about HIV like shingles, as the norm. Not that medical term only talked by the sister or nurse, that an ordinary person would understand, you see?

N. One other thing is that everybody does have his own role to play; for example, the businesses have to treat their own employees. As civil society we are the NGO, we have got to ensure that we support and mobilise. We should ensure that the government treats those who cannot be able to help themselves to afford the treatment or [access] free treatment in the hospital. The labour sector does ensure that there are policies within the company and they also ensure that there is no confusion in the company. The government has to ensure that it directs research, that is what we believe in. Not that they should have a last say in everything, not thinking that people who are doing this research are scientists. Our society does have this problem or this challenge. Can't we give a tender to one company to do a research, or either one scientist to do this research on this thing? How to ensure that people don not get sick through this and stuff like that. Then if they come with the results they should report these findings to the cabinet or either to the government. Then the government can pose some questions and look into the matter. After that they have to approve or either explain everything to the community.

I. Where does civil society fit in that role? Someone will conduct that research and they give it to government, is it not that the policy process is still isolated from citizens?

N. It is very important that we include civil society in every process or either in every stage in every platform of society. There is, for instance, the health right charter which involves people in health issues in every level? Even if we have conferences, big conferences, we have got to ensure that civil society organisations form part of that thing.

Just to see, and having a say, to listen to what is going on, to have a say in everything, every part of the society. Because the people at the end are going to be the end users of these things. They don't have to be sidelined, I don't like that.

I. That is what my thesis is about, how civil society can involve itself in the politics of [HIV/AIDS] in South Africa? Is there anything you would like to add?

N. I don't have much to say but that the government has to take control of most of the things. If I'm saying that I am trying to say that it has to ensure that those who cannot afford must be assisted to access the basics. Ensuring that people [come] before profit, every time for the basics mostly.

4. Interview with Zolani Mente at TAC Gauteng Branch, 25 June, 2004.

I – Interviewer (Alain Vandormael)
M – Mente (TAC member, treatment practitioner).

I. Basically my thesis is about civil society and democracy, in the sense of how the TAC has approached the government and that they have been very successful in this regard. What in your opinion has made the TAC a success, why do you think they have been able to pressure the government?

M. Because of their independency, they don't get any funds from the government and the people who are infected they are the ones in the forefront. And, they [TAC] are able to go and do research about things that are happening in other countries and they bring them back. The openness about it, they put their things on the table as the TAC – the bettering of the government.

I. You work in the townships specifically. What is your role there?

M. What I do now I just go to clinics, I ask for permission of course, and then go and talk about how important it is to know their HIV status, being positive at the same time, how can you deal with being positive, how can you live.

I. Is there a lot of stigma in the community regarding HIV/AIDS?

M. Yes, when we were picketing next to the US consulate in Kilarney, there was a guy who approached me from my branch, which is in Voslorus, he had just discovered he was HIV positive. […] He asked me how he could help this friend because in her family they are not giving her food and even the utensils they are using, they will never use again.

I. How much resistance do you come across when you go into the township? There is a story, I can not remember her name, she went into the township to reveal her status, I think she was a TAC member as well.

M. Yes, I remember that. Well, in Voslorus where I am living, no. I also target support groups so people do come to me an open about their status. But the problem is with their families. There are still a lot of people, they know there is HIV but there is not enough information for them. Things, difficulties I can talk about to access the clinics. Some sisters have a personal clash against the TAC, I don't know why. Other than that the community accepts me and are willing to listen. I also run workshops so they do come and pitch up and they ask questions if they don't understand it.

I. Do you receive much resistance from the clinics?

M. At a clinic there will be a lot of procedures before you start working. I am still waiting, we are supposed to start at J. Dumane clinic, it offers all the services but then the sister in charge said she must get the permission from the director and the director is unavailable. Before the TAC I was doing home based care, so it was much easier because I was under an NGO so to go to the clinic it was much easier for me. But now as a member of TAC it is not easy.

I. Do you think there will be a better working relationship between the TAC and the government and more specifically the clinics?

M. Oh yes, because I once attended a meeting with Dr. Tatanel, she is based in Alberton, she is the one who is overseeing the health issues. She, they are willing to work with us because they really need our help because we have got the information. And then, they have been trained in terms of how the treatment works and the HIV things. We can work hand in hand with them. But there are channels that we have to follow first.

I. Why do you think the government has taken this position on HIV/AIDS treatment?

M. Well, my personal view would be global politics first of all, because they are aware that ARVs do work, it is global politics more than anything.

I. Global politics in the sense of?

M. How they trade with other nations, because they target these nations so that they can invest in South Africa. That is when you think of the patent issues surrounding [anti-HIV] drugs.

I. What do you think of President Mbeki's views that poverty and malaria and TB and cholera, social issues so to speak, are the root causes of AIDS and not HIV?

M. I was surprised when President Mbeki said that HIV doesn't cause AIDS. I was a very shocked that a leader, our president could say that, because people would believe that, first of all. In fact they believed him. So people say 'what is the point of me protecting myself?' I think it was wrong. But if you are hungry and you need to have food on your table you will have to do something. If they go and commit crime or you go to jail and then what is happening inside there? Men do sleep with other men, you contract the virus. Malaria and all that stuff, yes, but HIV is the main problem.

I. What do you think of the government, in their words, that they will not be forced by the narrow treatment agenda of the TAC on ARVs? What do you think of their opinion about your organisation that you're just concerned about ARVs?

M. I think it is because they are not prepared, they are not prepared to face the issue of HIV/AIDS. They don't know how to tackle it. So they are trying to have escape goats and trying to confuse the community, especially South Africans. [They are saying] 'Listen this is not a major issue', yet it is. How many young South Africans are infected with the HIV virus? What they are doing now, they are trying to get this Lovelife and everything, this is not enough. What about those who are already infected? What are they doing about that?

I. Now that the TAC has managed to get the government to provide ARVs what is its role from now on? Before the role of the TAC was to pressure the government to get it to provide, but what does the TAC do now?

M. We want to pressurise in each and every province that ARVs must be available. But then we must provide them to local clinics because the pace that is taken by the government is not right. You will find that they will go and say ARVs are available in Johannesburg at the hospitals. But when you go there the procedure, the people will go through waiting lists, what is happening to them? They will take maybe 30 people a day. So what we are pushing on is that the government must decentralise and at the same time preach the part of adherence amongst the community. If our own government is able to generate our own medicines then we don't rely on other people.

I. A journal article that was published in the 'Afrobarometer' surveyed Africans' opinions of HIV/AIDS and they found that in South Africa most black people agreed with Thabo Mbeki's views about HIV/AIDS. Could this be because of peoples' patronage to the president, or people are uninformed, or…

M. Personally being black I would say that there would be a lack of information in the community. It is not easy for a parent to come and talk about sex to his child. For the government to say what it said and then the parents believe this, the community believed him [Mbeki].

I. Say there is another issue involved. I don't know if you know of a lady called Mandisa Mbali? She has written about the government's position on HIV/AIDS and she has seen an ideology in all of this in the sense that Mbeki is trying to move away from the idea that black people are sexually deviant, they have this sexual behaviour that is not civilised, and Mbeki wants to escape from this perception of black people. Mbeki is trying to say that HIV/AIDS is not an African problem, it is the scientific or medical problem, it is the West that has come and said that these Africans are all sick and diseased. Do you think people would agree with him?

M. Personally I would agree with him because you don't want to be seen as if you are the ones who are the parents of the HI virus. But because of our behaviour at the same time we don't want to listen. If you look at other countries when they started and we started and what they've done about it, there numbers are very low now today. Many black people don't want to listen.

I. Just a couple more questions. What do you think the TAC will do now that it has been successful? Do you think they will broaden their objectives, do you think they will now focus on issues other than ARV treatment?

M. To tell you the truth I don't know. But I think we will always focus on HIV issues and peoples' health in our country. So people can see that we are controlling the HIV issue now that we have brought it under control. We focus on other issues that are affecting South Africans

I. Will there not be a problem with regards to taking ARVs and the sophistication of these kinds of drugs; is that not going to be a problem for the TAC?

M. Yes, because you find out that people in the Natalspruit hospital in Katlehong is supposed to start on the 1st of July. But we went to visit the sites and we realised that people are not ready. As much as you can tell them this is how you take the treatment they do not adhere to the ARVs. We have to educate people. I've got a branch member whose already on ARVs, it has been two months now, I always check him, 'Are you taking your tablets'? I'm there for him, support of the family. And another thing: something goes wrong with you and being able to know what to do.

I. Now that ARVs are going to be provided what about the bigger social issues involved in this? Let us say, for example, that sanitation is not up to standard. How are people going to carry on taking these drugs when the water that they drink the pill with is going to give them cholera, for example? Do you think they are going to get around this? How are you going to address the problem of poverty in terms of taking drugs?

M. One of the things that we are trying to work with government is that if you are HIV positive and you are unemployed. […] You need to eat something and at the same time the government must facilitate the process of making sure that each and every South African does have access to clean water and then we as TAC we also look at those things in the near future. It is not simple on treatment because really you cannot take ARVs without food and people are living in a shack with no electricity. Certain ARVs need to be stored in a refrigerator.

I. Is this the Basic Income Grant you are talking about?

M. Basically it is the disability grant fund, the R740 that is given to everyone. Your CD4 count must be 200 or less. That is when you are already sick and you are not even on treatment. [What] if you are HIV positive, you are starting to get sick and you do your CD4 test and the CD4 count is 350, yet [you are] showing symptoms or signs?

I. What can people in the community do to partake in finding solutions to the HIV/AIDS problem?

M. First of all it will be having the knowledge about how ARVs work. If you have the knowledge then I think it will be… being open, talking freely about HIV. It is like talking about cancer. With HIV if you have got any symptom or any side effect you immediately go to the doctor so that the doctor can see what the problem is and treat it. And try your best to stick to your timetable – self discipline basically.

5. Interview with Charlotte Zitha at TAC Branch Gauteng, 30 June 2004.

I – Interviewer (Alain Vandormael)
Z – Zitha (TAC member and chairperson of the Kwateme Branch, Gauteng)

I. I don't know if you are familiar with the terms civil society and social movement?

Z. What I understand – I'm not sure if I'm quite right – it is something that deals with politics.

I. Do you see the TAC as an organisation or movement dealing with politics?

Z. Yes, because most of our issues are based on the people who will say 'Hey these are politicians'; because they always take action and they toy-toy around. It is the same.

I. Why do you think the TAC has been so successful in getting the government to change its position?

Z. Because when we started we decided to call our organisation the TAC. This TAC means Treatment Action Campaign, so whatever we want to do we always take action, and we are campaigning for that problem at that time.

I. What have you done to get the government to change its position? Why has the government changed its position, what has the TAC done?

Z. In an ARV program we used to see that there is a problem if a HIV positive mother is pregnant and she will deliver a positive baby. So we would sit as a committee and ask the government because there is money from the global fund for people with HIV. Let us ask the government to help, at least to save one of the two from dying, let the child be saved. So lets say we want some drug that can prevent the child [from contracting HIV] when the child is still in the mother's womb. So the government did give us the report and they said 'Ok we can give you Nevirapine and AZT to prevent the child from the mother's womb.' So they did do that and even now there is an ARV rollout program that is running around other places. It is because of us as the TAC members who did all that.

I. What do you make of the government's position on HIV/AIDS, on Mbeki's position?

Z. Well, we are having a problem with Mbeki because there was this report that says HIV doesn't kill, poverty is something that kills people. So we say that statement is not true. HIV does kill, so that is why we want everybody who is HIV positive and with a low CD count of 200 to get a social grant so that they can buy whatever, like food, nutrition, all this stuff that can boost their immune systems.

I. Why do you think he said HIV doesn't cause AIDS, or HIV is not a killer disease? Why do you think he says it is poverty which causes HIV/AIDS?

Z. Because if you don't get enough food you can end up doing the wrong thing, you can end up being a prostitute, or doing wrong things so that can lead you to get infected.

I. The government says that the TAC is only concerned about ARVs and Nevirapine and drugs, and they say that the TAC isn't focusing on the broader issues of HIV/AIDS. What do you think of that? Do you think the TAC is just concerned about drugs?

Z. No, we are not just concerned about drugs. We are concerned about everyone who is positive, who is not getting drugs. We want everyone to get treatment everywhere. We want every place to have ARVs, the rural areas, all of the places.

I. What is your role in the township where you work, what do you do?

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Z. My role, I work as a Gauteng practitioner. I do talks in the clinics and the hospital about HIV and AIDS and also about good adherence before you start ARVs. Also, I train NGOs, health workers and church based organisations, and individual people.

I. Is there much resistance to the TAC in the community, are people still very stigmatised?

Z. Yes, actually as the TAC we wanted to be the umbrella of the other organisations that are in the location. We want them to be with TAC, but the others they come to us and say no we cannot come and work together with you because you always toy-toy. They don't understand why we are toy-toying, because we don't just toy-toy. Before we toy-toy we go to that place and we give them a letter that on a certain day we will be toy-toying and the reason is 1-2-3. So if they want to comment on that they tell us before we toy-toy. We don't take any action unless we have permission.

I. So you mean they don't want to become associated with you because you are very political?

Z. Yes, that is the problem, the main problem we have in the locations.

I. These organisations working in the community, what were they doing before the TAC, what was their role or there function?

Z. What I've noticed since… most of them [civil society organisations] they are not only health issues. They are doing community issues or job creation. So we as TAC are on

health and we did tell them let us focus on this because HIV is the major problem, but still they refuse but others they do come and join the TAC. Out of 10 only 2 have joined the TAC.

I. What does the TAC intend to do in the community? Apart from providing ARVs does it have any other functions?

Z. We want everybody to have information about HIV and AIDS, about what it is, where does AIDS come from and what is the solution.

I. There was an article that appeared in the Afrobarometer trying to measure peoples attitudes towards HIV/AIDS, and they found that after a year of research that most black people in South Africa agreed with Thabo Mbeki's views on HIV. Coming from the location where you work, how would you understand it, why do people agree with Thabo Mbeki?

Z. I think most people around are scared to be open with their HIV status, and we in the TAC want everyone to be open with his or her status so that it will be easy for us to help them. To deny it is very dangerous because you will find at the end of the day you develop opportunistic infections. If I may say, how can we help you if you didn't disclose your status to us? So that is why most of our TAC members are HIV positive and they are open with their status, so that it will be easy for us as leaders to help them if we face problems. I think people are scared, they deny because they don't want to come out.

I. The TAC was a powerful organisation in getting the government to provide drugs, it got a lot of support from the media from other factions. Now that they have succeeded in getting the government to provide ARVs what is the role of the TAC now? Is it going to carry on being so important and popular or is it going to diminish and become a grassroots organisation?

Z. We are still going to carry on because other places do not have ARVs yet. So what we want is every sector to have ARV program. We are still going to push the government to help other sectors or districts to get ARVs. We want everybody to be treated the same and we want generic ones, generic is the cheapest.

I. Where were you a chairperson, in what location?

Z. Kwateme branch, I'm a chairperson of the branch. I'm having a support group, most of my members in the location are positive; half of them are positive half of them are affected. So during the week, especially Fridays we meet, and if it's a week for workshops I do workshops. We used to do project management because as a support group we must know how we are going to handle our things.

6. Interview with Xolani Kunene at TAC Branch Gauteng, 30 June 2004.

I – Interviewer (Alain Vandormael)
K – Kunene (Guateng Provincial Organiser)

I. Before we start what is your role in the TAC?

K. I am the TAC Gauteng organiser, so my task is looking after the well-being of volunteers in the province and also starting TAC branches.

I. I don't know how familiar you are with the words civil society and social movement. I don't know if you would see the TAC as a civil society organisation or as a social movement?

K. I think we are a civil society organisation looking after the interest of people living with HIV, with a special focus on human rights and treatment.

I. What do you think has been the key to the TAC's success in pressuring the government to reform its position on HIV/AIDS treatment?

K. I think the research we engaged in or having members who were supporting the TAC, especially volunteers. Being able to embark on big mass actions, those were the key things to change what government was saying up until now, the capacity of volunteers and to understand what is happening in issues.

I. Also in the numbers like popular organisations, mass campaigns, civil disobedience…

K. Those organisations like SANGOCO, COSATU and others supporting the cause, so far that is the strength of TAC.

I. It's a difficult question, many people in the media and a lot of academics have said that the TAC is a good thing for civil society and democracy in South Africa. What do you think of that, how do you interpret that, why is the TAC a good thing for civil society and democracy?

K. I like to agree with that notion, you see, when you deal with issues like HIV and having democratic government you always need a body that makes the government accountable – that will assist government in terms of taking decisions. So having an organisation like TAC, if you are a government employee and you see what's happening with all the protocols you can't raise your views but if you have a body like TAC then you will always know that those people will fight for you. Because what is happening now with TAC, we are not only focusing on rights for people living with HIV, we are also looking at conditions health care workers are working on, that is why we are going to have a summit starting on Friday this week. Just to look at the health system and the best ways to assist health care workers, nurses and doctors, so that we can have a proper health system that makes everyone to smile.

I. What do you think of the government's position previously specifically Mbeki's views that HIV doesn't cause AIDS, he has never met anybody with HIV/AIDS, or drugs are too toxic or expensive? What is going on, why has the government taken this controversial position?

K. Well one wouldn't have a specific answer on that question because you don't know what is happening in his mind. But one would say that the advisors to the president, sitting there with his advisors and when they come and advise him on that then he will come out and say those wrong things. At the end of the day it will impact on HIV education because now he hasn't come out and talked about the ARV program, to show the support for the program. People are still thinking that these drugs are toxic and HIV doesn't cause AIDS, and it really disturbs, in fact, it undermines the efforts that have been done by the other NGOs in training and educating communities. But I think basically what he was saying and it was wrong whether it was his advisors or his personal view those statements were very, very wrong.

I. Do you think, some people have said that there is an ideological aspect to this in that Mbeki is actually trying to protect the image of black people in Africa. That they are not simply sexually deviant. He is criticising this Western perception or even racist perception that black people go around sleeping with each other [etc…]

K. Well, we have different views one can think in that particular fashion that could be one of the reasons. But also one could say that the president is misinformed. I think the issue of HIV is ongoing and there are developments each and every day. As an individual you try and understand what is happening. The sad part of it is that he has tried to question these things in public, rather than questioning it in a bedroom situation or in the boardroom. So one could say that maybe it is the reason trying to protect blacks but the other view that he is misinformed, he is in the process of learning. To be a president doesn't mean you know, he is not a doctor so he doesn't understand these things. But also he is a man who believes in his views, so rather than listening and learning he decides to

come out and question all these things which sometimes as I have said hampers the whole education of HIV/AIDS.

I. And the TAC's role has been to contest this position of Mbeki's, to publicly oppose Mbeki views and say 'No Mbeki, you are wrong on this point, no Manto we do not believe in your garlic and your potatoes.' You know, the TAC has been very vocal ideologically in confronting government.

K. When TAC started in 1998 that was the whole idea to say we must clean up, we must educate, we must make sure that people who are misinformed are informed. That is why we are running a program like treatment literacy. In those programs we learn and we understand and we don't mind lending a hand to government and people like the president to educate him about HIV and AIDS, and the whole social science part of it. So we have been vocal and it has worked so far for us to come out and criticise what they are saying. I think ideally people who are living with HIV they have these problems and if you have a leader who sometimes goes in the other direction, pretend as if nothing is happening – it is wrong, and some people believe in their leaders. If the president is saying this, you have some government officials who stopped taking ARVs because they say they are toxic and they died in the process. If he at that time came out and said 'Sorry I was misinformed', maybe they would be still alive today. So that's why we need organisations like TAC in this country.

I. What is the relationship of the TAC to science and the medical establishment, in other words does it rely specifically on science to support its views, science as an ally in confronting government?

K. We try to use science and social responses, we look at what the science is saying now and what is happening socially. Hence when you look at our membership those are mainly people who come from communities, most of them are not even educated, they don't understand the big terms, these big words. But we try and link the two, we try to make sure that everybody understands what is happening. So we have relied on science…

I. Would it be incorrect to say that the TAC is just a voice piece for science, it is defending science in the name of civil society?

K. Oh yes, I think it would definitely be wrong. I think we also work with traditional healers. So based on that you can see that we are not only focusing on what science is telling us about research says. We are also trying to involve everybody to understand what is happening.

I. What do you think of the government's position that they won't be forced by – in their words – the TAC's narrow treatment agenda. In other words they claim that the TAC is not focused on the broader social issues of HIV/AIDS. All your organisation wants to do – so they say – is just to provide drugs, Western medical drugs, to the people. And that they don't into account issues like poverty and malaria and TB, what would you say to that?

K. That view is very wrong. The TAC I think in 2000 developed a document that was called the national treatment plan, and that those documents would not only focus on treatment using drugs but we also look at the well-being, the positive living and how to deal with issues in the poverty stricken areas. So we demonstrated that and looked at the networks that we have. We work with organisations like SANGOCO, work with organisation like BIG in trying to show that it is not only about taking treatment full stop. And the fact that we also started the program the treatment project, we are providing drugs direct to people. To say in a situation where like in Lusiksiki, it is not the same as Johannesburg, but them how can you help and how can you make sure that the ARV program is successful and involving other sectors of the community in making sure that the program is a success. So the notion that TAC is only looking at treatment only, it is wrong. We also support prevention, we distribute condoms through our branches, we run provision programs, we also train people on social grants how to access them, the use of human rights. So we are not focusing on treatment.

I. An article appeared in a journal called the Afrobarometer and they tried to measure black peoples' attitudes towards HIV/AIDS in a number of African countries, and in South Africa after a year of research they found that most black people agreed with Thabo Mbeki on HIV/AIDS.

K. It's true that people agree with the president, but not everybody of course. Why I am saying this because we have seen through education programs, like if you go to schools or if you go to companies there are still a view that this HIV thing is something that comes from somewhere and it is something that can be stopped. People are still questioning the history of HIV, if it started in say the US, how did it arrive in South Africa? Of course people are still questioning all these things, but through the awareness campaign ideally let us know that HIV is here while we allow the science research to take place. Maybe one day we will know exactly where this virus came from, but that should not be an obstacle for prevention programs, an obstacle for the treatment program. While we are treating and prevention and stuff like that we also have to allow the research to take place.

I. So people aren't informed, they agree… why would you say they agree with Mbeki, because they don't have the necessary knowledge or information about HIV/AIDS?

K. Yes, most people who agree with the president are those who are still lagging behind. Where they only know about HIV on TV or they see HIV education during the World AIDS day only, but they are not people interacting on a daily basis with the issue. People who study hard or do research on the issue they just interact at the given time and from there it is part of them. Some they believe that 'I've been around and I haven't been sick' and stuff like that. Others, I think I agree with the statement that first impressions last, when we started to know about HIV in the 80s they were showing us all these thin people, very sick individuals. And people thought that if you are HIV positive you must be like that. Now they don't see that happening, they still believe that HIV is not around, up until we reach that point then we will talk about HIV. That is why if you go to schools you will hear school kids will talk about HIV they pose questions in relation to AIDS, so

they can't differentiate between HIV and AIDS. But then a massive education program needs to be taken into the learners and companies so that people can understand also. And the ABC we need a strategy to change so that people can understand ABC in a different way, because now saying to a person who has been around, sleeping around or sleeping with partners for the past 20 years, and you tell him to be maybe faithful or to abstain, that's another issue. But then you need to try and walk that path that people have been walking and understand what is happening and then you can reach through their mind.

I. Just two more questions. My thesis is dealing with how civil society enables people to participate in politics, that it's not just something that happens between politicians. Civil society can act as that space in which people can engage politicians, and the TAC was a very good example of this, for example through mass civil disobedience campaigns and defiance campaigns and marches and picketing. People could with the organisation voice there disapproval or opposition to government. But now that the TAC has been so successful how do people continue to participate in HIV/AIDS decisions. Because government is still making decisions about HIV/AIDS but also scientists are now telling government how to make the decisions. […] So in a way the success of the TAC is limited the HIV/AIDS debate to politicians and scientists and once again normal people in the community are excluded from this process. What is the TAC doing, will it do something to ensure that people make an influence on this.

K. Presently in a stage where we are monitoring the ARV treatment program or the rollout and what is happening is what you call task teams. The task teams have TAC members and be part of decisions that are taken in those sides in the fashion that how do you rollout how do you inform communities and how do you monitor that people are taking treatment and stuff like that, that is at the local stage. Provincially, we are also in partnership or forming partnerships with provincial government to try and engage them and say these are the realities. As health institutions you work from Monday to Friday, Saturday and Sunday – we don't know what's happening, so as TAC we gather this information from our local branches and these task teams, we inform the province, we move together. It's tough, it's not easy, we are dealing with people who have been around

and know these things, but then we have to influence those decisions that are taken in the province. Because if you look at the ARV program the way they stock medication it is done in the provincial and then it is distributed to sites. So that's where we feel that sometimes you have a situation where you don't find medication in some institutions and they tell you that these medications have not been delivered. So we are trying other systems and what is the best way of speeding up the processes. On a national level, where you have big guns and big politicians, we are also trying to influence through SANEC we have our members who sit there and raise the voice. So now it has moved to the point that we need to break ourselves, unlike when we do massively when we rush to the streets. Now we are no longer doing that but we are trying to influence these committees, these task teams. I can tell you that now we are going to have some meetings with local government, in Urkeleni, Tswane, etc, to try to say this is how far you have gone starting from April and what you have done now and what is happening now and how do you build a common understanding in all this. So we are now sitting in the boardrooms, unlike before.

I. Don't you think it is a problem that the TAC may become institutionalised or bureaucratised under the state?

K. The way things are going we try by all means to maintain our autonomy, we try by all means to remain TAC. A TAC that is well known a TAC that can make noise, a TAC that doesn't budge to just anything. So if there is no agreement in the boardroom of course we go on the streets, so they know that – like last week we were there at the US consulate, we were picketing there – so we still have that TAC but now we are more focusing on TAC in boardrooms.

I. So it is still a very strategic organisation, at one time you assist the government on the rollout of ARVs, but if things don't go right, if government is reluctant you become confrontational and antagonistic.

K. The same TAC…

I. So your success isn't going to change the organisation?

K. It won't in the near future.

7. Interview with Zackie Achmat at the private residence of Judge Edwin Cameron, 7 July 2004

I – Interviewer (Alain Vandormael)
A – Achmat (Founder, chairperson of the TAC)

I. Essentially my thesis is on civil society and democracy, focusing specifically on the TAC. When I have given my proposal to academics they have always asked me why do insist on calling the TAC a civil society organisation, they say 'Wouldn't it be more appropriate to refer to them as a social movement?' I'm not sure if you are familiar with the differences in the terms but what would you see the TAC as?

A. It's a hybrid. If you look at our organisation in terms of membership we have about 9-10 000 registered members on our database. There are members organised in branches at community level who take decisions pertaining to their local areas and elect delegates that go on a national conference where decisions are taken and they elect the NEC (National Executive Committee). We are formally organised that way in six out of the nine provinces across the country. The majority of our members, I would say a good, almost 80%, are aged between 14 and 24. The majority of our members are women, the vast majority of people are African and a very clear majority are unemployed. So that's at the level of the organisation, more that 90% of what we do never gets into the media and that involves educating people who live with HIV and educating nurses, doctors, health care workers, about basic medicines, basic positive living, ARV treatment, what it is – basically what we call treatment literacy. That involves also an understanding of the political economy of health. So at that level the TAC resembles a social movement that

has certain political or certain social demands which it places the state and on private actors, and it follows up on those demands and uses a variety of strategies of democratic participation, including petitions, marches, demonstrations, engaging parliamentary committees, engaging statutory bodies, litigation and civil disobedience. And in that sense it resembles a social movement, in a different sense we also function as a NGO because we are delivering certain services like our treatment literacy. We have full time staff (I'm not a full time staff member for instance) but we have more than 40 full time paid staff members across the country. We've gone from an organisation that had no budget in the first two years, less than R200 000 in the first two years. The organisation this year spent more than R15 million. […]

I. Commentators in the media and academia have said that the success of the TAC in pressuring the government's treatment policy is actually a victory for civil society and democracy in South Africa. How would you see those comments? What is it particularly about the TAC that has substantiated the idea of democracy in the country?

A. Well there are different levels in which the TAC can be said to have tested democracy and governance, not only in South Africa but globally. If you look at the TAC's work with other civil society actors both nationally and internationally like the trade unions, medicines sans frontiers [etc], we've set a standard on issues of corporate governance, how drug companies research, how they use their research, how they make profits, their exclusion of medicines, intellectual property, WTO rules, that are so arcane to most people – like even patents. What we've done is made those debates concrete to ordinary people and so someone in Orange farm or Diepsloot can relate equally to the question of patents in a way that many people around boardrooms will understand the issue of patents. In that sense, at one level, there has been a corporate accountability of bringing, of holding account corporate institutions but also international agencies like the WTO. In South Africa specifically following the denialism of the president, the obfuscation the vacillation, all those things relating to denial of access to treatment, denial of access to medications to prevent mother to child transmission and so on. The TAC strengthened civil society participation in both the parliamentary process for instance – we must have

given evidence to parliament about 10 times, not only did we give evidence we marched to parliament to make people aware, make the country aware of the social issues and so on. We've tested many of the statutory and constitutionally – what are known as the chapter 9 bodies, the chapter 9 institutions, things like the gender commission, the human rights commission. In TAC you will find that at provincial level of our leaders they will know about the medicines control council. For me citizenship is not about nationality, citizenship is about participation and understanding, and I think that is what our leadership and our members understand that we have become citizens rather than subjects, citizens rather than recipients of the beneficence of the state or of corporations.

I. I'll get back to that point later on, but what do you make of the government's position on regards to HIV/AIDS treatment, why have they taken this position?

A. Well I think it is a question that everyone asks, it is a question that is fairly complex. I think the first thing is the president is a denialist. The second thing is initially the costs of medicines. […] In that sense there was a cost element. The president's understanding of the West's perception of Africa as a continent of beggars, continent of black malgovernance, continent of poverty, continent of sexual promiscuity. And so in the president's mind AIDS pathologises poverty, sexuality and race, and it becomes a signifier for all those things. It is a reaction to the West's perception of Africa but it also can be historically contextualised in his absence from our continent almost his whole adult life up to now. […] The government's policy, and again it would be a mistake to see the government as homogenous because there are government officials at clinic level at district level, provincial, national level, government in different departments, at the executive level and in the legislature. At various levels there have been people who have supported us, nurses, doctors or department of health officials at provincial or national level have been very supportive towards our work. In that sense government policy, what the president induced was uncertainty…

I. Two questions, what do you make of the government's opinion that they wont be forced by – in their words – the narrow treatment agenda of the TAC, and related to that

question would it be fair to say that the TAC has been rather hostile to the idea of looking at HIV/AIDS in a broader social framework in terms of poverty, gender inequality, malaria, TB. Would it be far to say that the TAC has tried to reduce the discourse of HIV/AIDS in this country to a question of treatment, specifically ARV treatment?

A. I would say that is profoundly stupid. The only people who have no understanding of our work or who has not studied every single document and who has no account of the history of where many TAC leaders come from – would adopt that attitude. Many of us participated in the development of the national AIDS plan in 1992-94 which clearly outlines the link between migrant labour and poverty, the issues of gender inequality and poverty and HIV and placing people at risk, the issues of lesbian and gay inequality, sex workers and a number of things. I think what would be fair to say is that many people in the AIDS movement got divorced from the public health agenda and what TAC has done is reversed that. We have actually reversed what people within the AIDS world and the broader AIDS bureaucracy were ignoring as a public health agenda. So the TAC has not only supported government in court cases on medicines but we've engaged in issues such as the competition commission, and our work has always been done with a focus on making health care accessible and affordable to all people. It wouldn't be a mistake to say that the main focus of our work has been HIV/AIDS treatment and prevention, HIV/AIDS within the health system, that wouldn't be a mistake. But to say that we ignore the issues of poverty and malnutrition and so on is just plain stupid. You might hear I am very intolerant of that position because it doesn't take into account the education we give our branch members, what we learn ourselves, all of us, and the context in which all of live. That the vast majority of our members live in extreme poverty, so how could we ignore poverty? As one of the women in Lusikiki who got ARV treatment: do you need water or do you need ARV treatment. She said no ARVs allow me to walk to fetch the water…

I. Could you say what happens if the water you drinking gives you cholera while you take the ARVs?

A. Well, will you have cholera before or after, you may have it before or after whether you are taking ARVs or not, the question is making sure that everyone has access to clean water. In the context of HIV clean water is a very important factor because of parasites and any number of illnesses you could get, and a much more rapid progression of AIDS and so on. There is no question that we will tell any of our branch members that you would have to clean your water, make sure you drink boiled water. […] Our immediate demands are to save lives and to improve the health care system and to make a democratic state function. […] On the other hand you have government which says TAC only concentrates on ARVs but they ignore the entire history and complexity of the issue of ARV treatment. It involves… we start from the premise that HIV is a deeply political issue because of the relationships between men and women, between black and white, racial relationships, racial inequality, wealth, class inequality, inequalities between countries, relationships between citizens and global institutions. We have engaged WTOs, whether it is engaging the UN, whether it is engaging the WHO, whether it is engaging the US government, we have been active on all those fronts, not by our selves, always in conjunction with our allies and understanding the entire complexity.

I. Do you think then – you said earlier that 90% of what does hasn't been reported, would you say that is primarily the fault of the media in having perhaps presented an image of your organisation as focusing ARV treatment as a weapon against government policy?

A. When one engages the market orientated media you shouldn't have expectations of that form of media to do anything other that sensationalise, trivialise, mischaracterise and misrepresent. If you start from the assumption that it is going to give you a full picture of everything then you will be sorely disappointed. We have never had that expectation of the media, despite that there has been too much of a focus on me personally for instance, and yet the only time we get stories in was to personalise stories in the media. So that they love generally having a drama that they can report. I think that the media – and that is another test of our democracy – that the media has been the one institution that has reported the debate and its various sides and actually held accountable the minister of health in a way that she has not been held accountable by parliament. There are many

things one can criticise the media about, but I would say all in all they have represented a skewed picture of what the TAC has done and we have suffered for that… skewed in terms of the focus on ARVs, skewed in terms of individuals like myself […]

I. What is the relationship between the TAC and the scientific and medical community? Would it be fair to say in many respects that the TAC has been a voicepiece of science?

A. We have tried to base all our work on serious science. In some ways we have compromised on that. I remember – when we started our MTCT campaign you may remember that short course AZT which was piloted in Kayelitsha, the pilots which were cancelled across the country, that was the standard we wanted to use. The Ugandan Nevirapine study came out and our minister of health said this is the cheapest and most effective and much more safe. Someone had pointed out that resistance occurs much more rapidly with Nevirapine and we internally with our allies said we should oppose Nevirapine and stay on AZT as an example and everyone said look the government has made the policy choice to use Nevirapine. It is probably the only thing that can be used as a starting point in poor communities, one dose to mother and child and you prevent more than 50% of transmissions even in breast feeding communities. Yes, we have had to familiarise ourselves with scientific issues that go way beyond any user of health care generally does. So we have both acted as the conscience of the scientific community and very often as a voice. Because very often the scientific community, I mean if you take the debate of denialism, the South African medical association added its voice much later. […] The scientific and medical bodies came much later and so in that sense, yes. We have also been a voice for ordinary health care workers who face the fact that they face death on a daily basis and cant do anything about it and we have been a voice for there frustration as well. I would of hoped that in the Nevirpaine issue that we could of stuck to the question of AZT but now we are going back to the question of using AZT and Nevirapine together, I hope. It's a complex thing.

I. Not many people have touched upon this in terms of the TAC's ideological standing on HIV/AIDS, for example when Riaan Malan said that HIV mortality rates were greatly

overestimated in this country and Nathan Geffen immediately responded by saying here is the evidence to refute your claims, or when Mbeki said HIV/AIDS is only the 12th biggest killer. It almost seems that your organisation has been concentrating on ARV rollout but also on the ideological aspects of orthodox science.

A. The question is for us because it goes about our health and because there is such an enormous crisis the only thing we can rely on is scientific evidence based arguments. In that sense the assault that has come from the president and acolytes like Riaan Malan have been on the science, and have been on the epidemiological projections and so on. We have never used over-estimations, in any of our work. In fact we don't use what the ASA model people say – they use realistic assumptions. We use conservative assumption not even realistic ones. In a sense we don't want to give hostages to fortune in a political argument because what has happened is that science has been politicised. Now it would be stupid to believe that science is not political in any way. […] The politicisation of medicine, because you don't speak about problems in your hospitals about your under-resources because you fear that your budget, your subsidy from the state would be cut. So in many ways our scientists have not spoken up about issues of undue pressure and the lack of independence of scientists and that has been at the forefront of our mind. It is in our interest not to have a craven scientific community either to the commercial world or the political world because people who need medicines and a decent health care service. We want the best that science can provide. You are right that we have always responded and we have always tried to respond in the most scientific way possible.

I. Getting back to citizen participation in politics. Essentially what the TAC did was enable citizens to engage in political issues and policy decisions, specifically through civil disobedience campaigns, protest and marches. But in many respects could you not say that now HIV/AIDS discourse has become limited or confined to relations between scientists and politicians. So we have this whole process going on where science dictates policy, government's opinions and policies are determined by what science is saying now and so you have this process happening at the top where people at the bottom are all of a

sudden excluded. In other words, where and how can citizens continue to participate in HIV/AIDS discourse in light of the TAC's success?

A. I'll first speak about AIDS, and then I'll speak more broadly about health. In HIV/AIDS I think there is still an enormous role. […] Concerning evolving treatment for HIV, whether its new classes of drugs, drugs that are still expensive like protease inhibitors, there is still an enormous amount of work for civil society to do but in the case of microbicides to assist prevention, in the case of vaccine development and also I believe in the area of making condoms more useful whether it's the female condom and so on making it more exciting to use in different ways like that. But also if you look more broadly at social science, I went to this ridiculous conference of SASA…

I. Did you not bump into one or two of my professors there?

A. I probably may have and I probably offended all of them. I was quite horrified because even people who had no formal education within our education system have much greater scientific understanding and compassion on the issues whether it's the impact of HIV on families or whether it's the science of ARVs, whether it's a question of politics and poverty, than all of those sociology professors in there questions demonstrated. There was not an ounce of understanding or compassion of the urgency of the epidemic. It was almost if the sociologists wanted to insulate themselves from the controversy surrounding the epidemic. […]

I. What is the role of the TAC now that it has pressured the government to reform its treatment position?

A. Most of our work as I said goes unnoticed but the need to scale that up and essentially that is to develop a cadre of treatment literate people that extends far beyond our own membership into support groups, community groups, into NGOs into trade unions and so – and into sociology – to make them understand the science of ARVs, the medicines that you use for opportunistic infections. […] What the politicians have thrived upon is the

scientific illiteracy of particularly middle class people. […] So our job is to scale up our treatment literacy. More than that the ARV rollout presents what one of my colleagues Lydia Cancross (she is a doctor) says 'It's the greatest challenge to the public health service but it's also the greatest hope for the public health care service.' For the first time you will be able to place equipment, if you deal with it on an equitable basis, but invest in health care recourses and human recourses in the poorest areas, and that is our job. We are going to ensure that the TAC assists and leads to the discussion on the creation of a national health service in the country.

I. When I asked one of the TAC members at the Gauteng branch what the TAC would do he said there was also a number of TAC members sitting in committees with regards to the implementation of ARVs. Do you know anything about that?

A. At various levels we participate at provincial level, provincial AIDS council, and the ARV rollout plan we are part of those decision-makings. At district level people here in Gauteng people participate in the provincial AIDS councils. The difference between our participation and people who sit there to rubberstamp government decision or indecision (more often indecision than decision) is that we go there with prepared documentation prepared understanding and a clear position on what needs to be done.

I. There is no risk of the institutionalisation of the TAC now…

A. There is a serious risk of that. The risk is inherent within the situation in the country that you are going to have people who have access to medicines and people who don't have access to medicines. If we don't maintain the unity between the poorest people in the country who don't have access to medicines and those of us who are advantaged and privileged to have access to medicines then TAC can become, it shouldn't become, but it can become a voice of people with access.

I. One final question, I think I know the answer to this question, but I'd like to get your opinion on this. A journal called the Afrobarometer did research on Africans' opinions

and attitudes towards HIV/AIDS and they came up with data saying that most black people in this country supported Mbeki's views and government's views of HIV/AIDS. What would you say of that?

A. You know, I haven't seen the study so I cant comment with clarity on what the study actually says and what the shortcomings are. What I would say is this, that there is enormous, enormous levels of confusion and if you are someone who is directly at risk of HIV transmission and you don't have clear scientific information or clear medical information and TAC despite all of its public profile in all of our working communities still only reach a small minority of people and that is why we say it is the government's job to do what we doing. So there is enormous confusion even among health care workers. […] Within the health care service particularly with nurses and doctors the majority of doctors who practise are people have never seen an AIDS case, the majority of nurses who practise are people who have never seen an AIDS case. Or let me phrase it, they have seen AIDS cases, people presenting at clinical level but they have never in their education been presented with it as an issue to study as an issue of how the disease develops and so on. So I wouldn't be surprised if a significant majority of people supported the president's viewpoint but that's neither here nor there, the majority of people support the death penalty.
[…] I wanted to just make a remark about civil disobedience. Civil disobedience is one strategy that we use at the very end of our tether with the government and that's not because we believe that we have an illegitimate government because we do believe that we have a legitimate government. People who are politically ignorant would argue that you can't have civil disobedience against a legitimate government. We recognise the state, we disagree with this particular policy of the state and we are prepared to break the law and face the consequences of our actions. That was a very limited period of our action between March and say August of last year 2003. That was the period in which we both activated and suspended civil disobedience over two periods. It caused enormous discussion and tension in our organisation because we concentrate enormous pain and anguish and mourning and so on, and TAC is a productive outlet for many of the deprivations that people have to access to health care services and in fact in access to life

itself. The leadership of the TAC put our necks on the block when we suspended our civil disobedience because the vast majority of our members did not want to suspend civil disobedience. But leadership is precisely about that, you lead because you have a much broader picture of the world. Sometimes it means going against a popular opinion within one's own organisation if that is necessary.