

# The emergence of effective ‘AIDS response coalitions’: A comparison of Uganda and South Africa

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**Leaders, Elites & Coalitions**  
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# 1 Introduction

A quarter century into the AIDS epidemic, it is increasingly recognised that ‘AIDS leadership’ is crucial to sustaining and improving national and international responses. However, the notions of leadership generally, and AIDS leadership specifically, are ill-defined and the literature generally weak. Defining AIDS leadership and describing what it entails is difficult, for at least two reasons: (1) the qualities of leadership itself are hard to pin down and (2) what is required for successful leadership is highly context-specific and therefore hard to generalise. What is clear is that an effective AIDS response requires cooperative collective action on the part of a wide range of actors at all levels of society. In cases where countries have been successful (e.g. the much-cited Ugandan ‘success story’), this is often attributed precisely to such broad and concerted action across a society (Thornton, 2008; Patterson, 2006; O’Manique, 2004; Low-Beer and Stoneburner, 2004). Members of political and economic elites, state bureaucracies, civil society, the private sector and even multilateral institutions and donors are required to participate in the formulation and implementation of progressive policies on AIDS prevention and treatment. That this presents a formidable leadership challenge is widely recognised, but in both theoretical and policy discourses, solutions to complex collective action problems are hard to come by.

One possibility is represented by an emerging perspective focusing on the role of leaders in forging ‘coalitions’, defined by Leftwich and Hogg (2007) as “an association of groups and organisations working to resolve specific problems . . . that are beyond the capacity of any individual member to the coalition to resolve. . .” For reasons briefly outlined in the next section, I believe this to be a highly promising perspective. I therefore propose a definition of effective *AIDS leadership* as the ability to mobilise successful *AIDS response coalitions*. Instead of a psychologistic focus on the individual leader (the so-called ‘big man’ theory of history), leadership is approached relationally — i.e., leadership refers primarily to the processes involved in resolving the complex collective action problems of coalition-building for policy formulation and implementation. The key research question of this study could therefore be formulated as: *under what conditions, and by which processes, do effective AIDS response coalitions emerge?* And importantly, how can the international community encourage their formation?

It is important to note that the question of AIDS leadership is *inherently normative* (it is certainly possible to be a ‘bad leader’ and to build coalitions around harmful policies) and *inherently political*. It is political because leadership occurs (and is required) precisely where contestation takes place over

principles, policies and resources. Any reflection upon AIDS leadership must therefore necessarily be a political analysis and take account of political dynamics and the institutional and historical context within which contestation takes place (which shows significant variation).

In order to explore what is required for effective AIDS leadership, this paper compares aspects of the AIDS responses in South Africa and Uganda. In both these countries coalitions mobilised by and in civil society seem to have played a key role in building broad societal partnerships. While states must bear the primary responsibility for HIV/AIDS interventions in hyper-epidemic countries (specifically large-scale prevention and treatment programmes), the complex collective action problems these entail cannot be overcome without such partnerships. The paper focuses on two prominent civil society organisations that are widely seen as world leaders in the AIDS response – The AIDS Support Organisation (TASO) in Uganda and the Treatment Action Campaign (TAC) in South Africa. Both have played crucial roles in their countries' responses, and in both cases their success is to a significant extent a reflection of their ability to mobilise broad coalitions to address the HIV/AIDS crises in their respective societies. It is the belief of the authors that these examples are instructive in understanding the relationship between “civil society leadership” and the broader AIDS response. However, while there are important similarities, there are also significant differences between the organisations and the contexts within which they operate. Any study must therefore include rich contextual description that takes into account these differences.

South Africa and Uganda are both sub-Saharan African countries with large-scale generalised HIV epidemics. However, there are significant differences: Uganda's epidemic is several years ahead of that of South Africa; the former is much poorer, with weaker health infrastructure and depends on foreign aid to a much greater extent; and the histories and political systems of the two countries differ significantly. Both are held up as exemplary, but for very different reasons: the state-led ‘multi-sectoral’ response in Uganda during the 1980s and 1990s and particularly the leadership of President Yoweri Museveni are widely praised (see O'Manique, 2004; Low-Beer and Stoneburner, 2004). South Africa, on the other hand, is seen as the ultimate example of a failure of leadership, characterised by state-sponsored AIDS denialism, a half-hearted prevention programme and the deliberate obstruction of AIDS treatment in the public healthcare system (see Cameron, 2005; Natrass, 2004; 2007; Oppenheimer and Bayer, 2007).

Both TASO and TAC were founded by charismatic and inspirational leaders who were personally affected by HIV. Noerine Kaleeba — then principal of the School of Physiotherapy at Uganda's only teaching hospital — founded TASO with a small number of colleagues and friends after she lost her husband to

AIDS in 1987. At the time no life-saving treatment for HIV/AIDS was available, and the founders were responding primarily to the human tragedy caused by widespread stigma and discrimination (both within the healthcare system and the wider community) which condemned patients to lonely and undignified deaths.<sup>1</sup> The TAC, on the other hand, was founded by seasoned political activists led by Zackie Achmat (who had been living with HIV since 1990). By this time (late 1998) Highly-Active Antiretroviral Therapy was starting to reduce AIDS deaths dramatically in industrialised countries. The primary motivation of the founders was therefore outrage at the fact that these drugs were almost entirely unavailable in Sub-Saharan Africa and other developing countries, except to the very small proportion of patients able to purchase them privately.<sup>2</sup> While TAC also responded to stigma and discrimination,<sup>3</sup> the focus on treatment access put it on a more political footing from the start.

While both organisations have become the faces of their countries' AIDS crises and have faced similar challenges (e.g. the transition from charismatic leadership to formal, professionalised management, maintaining independence from donors, etc.) there have also been substantial differences in their development and their respective roles in the national AIDS responses. TASO became the major provider of both medical and social support services to HIV/AIDS patients in Uganda. It is a large and professionally-run organisation with a relatively formal and inflexible management culture. The TAC remained a smaller and more nimble activist organisation, staffed largely by politically-motivated individuals. Its focus has remained advocacy and political mobilisation. These differences were conditioned by the initial motivations of the founders (the TAC was always much more oriented towards political activism/advocacy and TASO towards service delivery), but crucially, also the differences in their contexts. Contextual differences include levels of development and state capacity (South Africa has a relatively sophisticated healthcare system and vastly greater state capacity to provide services), in political institutions and cultures, and in the roles of other influential actors such as donors.

This paper attempts to describe and analyse how these contextual and structural factors have shaped the development of the two organisations (and how they have in turn shaped the societal AIDS responses in their respective countries), while at the same time acknowledging factors related to individual agency (such as the actions of founder-leaders like Achmat and Kaleeba or individual

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<sup>1</sup>Interview with Noerine Kaleeba (TASO Founder and Patron).

<sup>2</sup>Interview with Zackie Achmat (TAC Founder and Deputy General Secretary).

<sup>3</sup>The TAC's famous "HV-positive" tee-shirts (which have become a globally recognised symbol of the fight against stigma and is used by activists across the world) were first printed in response to the murder of Gugu Dlamini, who was killed by a mob after publicly disclosing her HIV-positive status.

political leaders like Presidents Museveni and Mbeki) that have impacted on this development. It starts by briefly examining the question of ‘AIDS leadership’ and how this relates to the notions of social capital and coalitions. Elements of the the history of the two movements are recounted while describing the most salient aspects of their respective political, economic and historical contexts. An attempt is also made to account for coalitions as emerging from the mobilisation (by leaders) of elite networks. Owing to their substantial impact on the national AIDS responses, the role of donors is discussed in some detail before turning to the internal evolution of the organisations with respect to leadership, management and structure. Finally, it considers implications for civil society leadership and examines potential policy implications, particularly for multilateral agencies and donor organisations that wish to support civil society leadership for effective AIDS responses.

## 1.1 Research design and methodology

The highly context-specific nature of AIDS leadership, as well as the fact that the theoretical approach outlined above can provide no more than a frame for historical analysis, means that this study must employ a rich and detailed empirical account or ‘thick description’ (Geertz, 1973). It therefore employs primarily historical and qualitative methodologies, including documentary/archive sources and in-depth interviews with key informants.

This study builds on an existing research project on AIDS activism in South Africa (see Grebe, 2008b) for which a range of in-depth interviews were conducted with TAC leaders (particularly those who were involved in the founding and initial years of the organisation), other civil society leaders as well as key allies in the scientific and medical communities. The research was conducted with a view to establishing the key factors behind the movement’s apparent success — in particular the radical change in government policy with respect to antiretroviral therapy with which it is widely credited. Major focus areas included the role of individual charismatic leaders, decision-making and governance processes, leadership development, the challenges of building of formal management systems and establishing international and domestic civil society alliances and solidarity networks. For this comparative study further in-depth interviews were conducted with key figures in the Ugandan AIDS response, including former and current TASO leaders and staff, other civil society leaders, key development partners and senior figures in the Uganda AIDS Commission. In addition, relevant policy documents and organisational reports were reviewed. Field work was conducted during 2007 and early 2008 (TAC) and October 2008 (TASO).

## 1.2 Theoretical framework: leadership as mobilising coalitions

An important objective of the broader research project of which this study forms a part, is to develop a theoretical framework to frame a historical comparative analysis of AIDS responses and an account of coalitions around treatment access nationally and internationally. For reasons of space it cannot be presented here in any detail, but a brief overview follows.

As intimated earlier, the leadership challenge is approached as a set of collective action problems (since AIDS requires society-wide action). It draws on traditional approaches to comparative politics like *historical institutionalism* and (in order to understand the role of civil society) *social movement theory*; it also draws on the emerging field of ‘network theory’ (and related work on ‘social capital’) and on the idea of elite ‘coalitions’ in an attempt to integrate both structural and agencial factors into accounts of the political resolution of collective action problems.

As argued earlier, AIDS leadership is highly context-dependent. The institutional arrangements of any given polity profoundly shape the opportunities and incentives facing leaders and elites<sup>4</sup> (Skocpol, 1995; Hay and Wincott, 1998; Thelen, 1999; Pierson, 2000; Pierson and Skocpol, 2002) and are therefore highly relevant to the processes I wish to study. While historical institutionalist scholars are interested in macro-level historical changes that shape institutional and economic structures over time (see David, 2001; Pierson, 2004), the perspective is nevertheless useful to a more micro-level account of AIDS policy negotiation which tries to be sensitive to the contextual factors that shape the process. Historical institutionalist accounts of the way in which culture (including political culture) becomes embedded in institutional arrangements and patterns of political behaviour<sup>5</sup> can help us make sense of the relationship between culture and societal AIDS responses, which the preliminary empirical evidence presented in this paper suggests is a major factor in explaining variation between societies. The notions of *path dependence* (the ‘self-reinforcing’ persistence of institutional structures or their change along distinct trajectories) and *critical junctures* (moments of discontinuity and major institutional upheaval) may help us understand the evolution of AIDS policy within a historical context (Collier

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<sup>4</sup>While attention to the interaction of ‘interests’ and ‘incentives’ are highly useful in trying to understand how actors respond to circumstances, it is important not to let this degenerate into a simplistic and deterministic analysis which reduces agents to repositories of interests that respond to incentive structures in an automatic or fully predictable way. I will try to retain a place for human agency in my analysis.

<sup>5</sup>Douglass North (1990; 2005) is a prominent theorist of the relationship between culture, institutional change and economic performance. However, he has been accused of employing an essentialised notion of culture insensitive to the subtleties of historical change (see, e.g. Heydemann, 2008).

and Collier, 1991; Collier, 2007; Boas, 2007).

One problem all macro-historical analyses face is the question of how much explanatory weight to attach to structural and contextual factors and how much to individual agency. One of the benefits of the idea of ‘coalitions’ is precisely that it may help us to bridge this structure-agency dichotomy. Yashar defines coalitions as follows:

... coalitions are defined as alliances among social sectors or groups. They provide the organizational framework for delineating who sides with whom, against whom, and over what. Coalitions bring together groups or institutions with heterogeneous, divergent long-term goals that they are willing to sacrifice for some intermediate, collective goals. (Yashar, 1997:15)

This perspective therefore introduces a focus on human agency without neglecting the structural and contextual factors that determine the possibilities open to individuals and groups.

Furthermore, while institutionalist perspectives like those outlined above help us to understand the historical boundedness of AIDS responses, they do not yet offer a way of accounting for the role of civil society organisations and social movements. A more specific theory of civil society mobilisation and political contestation is required. While at times I draw on *social movement theory*,<sup>6</sup> in particular the idea of political opportunity structure, the perspective also has serious limitations. While it provides powerful tools for analysing the impact of political context on movement success and failure, I have argued that it exhibits a state-centric and domestic bias, which limits its usefulness in the analysis of transnational social movements — or movements that rely on transnational processes for a substantial part of their influence (Grebe, 2008a).<sup>7</sup> AIDS activist movements are prime examples of social movements that have transnational characteristics.

In the context of civil society, we can think of coalitions on two levels — though they cannot be rigorously separated — (1) the mobilisation of civil society coalitions and support networks to influence policy and institutions, and (2) the building of broad and diverse AIDS response coalitions (incorporating

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<sup>6</sup>Social movement theory focuses on the structural preconditions and means for collective political action, and considers three broad sets of factors: (1) the structure of political opportunities and constraints facing the movement; (2) the forms of organisation (both formal and informal) available to participants (also called ‘mobilising structures’); and (3) the collective processes of interpretation, attribution, and social construction that mediate between opportunity and action, known as ‘framing processes’ (McAdam et al., 1996:2).

<sup>7</sup>Some social movement scholars have acknowledged this challenge (e.g. Tarrow, 1996) and ‘new social movement’ theory has attempted to offer a more sophisticated analysis that does not fall prey to structural determinism (Buechler, 1995). See, for example, Touraine (1981) and Castells (1998).

civil society, state and international actors) in order to strengthen the AIDS response society-wide. The former is closer to what is often referred to as ‘advocacy networks’ in the literature (see Grebe, 2008a; Keck and Sikkink, 1998) and are used primarily to mobilise resources (both material and symbolic) in order to gain influence. AIDS response coalitions are closer to what is referred to by Leftwich and Hogg (2007) as ‘developmental coalitions’, which need to be flexible and broad in order to formulate and implement appropriate policy.

In order to deepen the notion of coalitions, I also draw on network theory and the related field of social capital. Increasingly, network perspectives on society are adopted that focus not on the inherent characteristics of people (‘nodes’) but on the relations between people (‘edges’). Approaches like ‘social network analysis’ focus on the webs of interrelationships between individuals. (See Wasserman and Faust (1994) for an overview of the theory and techniques of social network analysis.) Individuals (‘actors’) are considered primarily as nodes in the network, rather than as the repository of individual agency. A basic premise of network thinking is that outcomes are shaped more by the ‘network effects’ that result cumulatively from the relationships between nodes than by the characteristics of the nodes themselves. Applied to social networks, this view holds that an individual’s significance in a social configuration results from the ties (strong or weak, many or few, etc.) between that individual and others in the network.<sup>8</sup> There is also a substantial literature on social capital, which provides strong evidence of the effects of social networks on economic outcomes (Hjerppe, 2003), with a particularly substantial body of work on job-networks and labour market outcomes (Granovetter, 1974; Montgomery, 1991; Calvó-Armengol and Jackson, 2004; Ioannides and Loury, 2004). In earlier research (Grebe, 2008a;b), I argued that the impact of AIDS activists derives from their roles in (transnational) ‘networks of influence’ that comprise a wide range of actors (including domestic AIDS activists, members of international activist networks, other civil society actors, international NGOs, donor governments and grant makers, members of scientific and clinical communities, individuals within state and semi-state institutions, etc). Networks are employed to mobilise both symbolic and material resources, and it was argued that these networks form the basis (“infrastructure”) of AIDS response coalitions that emerge on the basis of moral consensus (Grebe, 2008b:30–33). If networks indeed form the basis of coalitions, an ability to tap into or build networks and to mobilise (material and symbolic) resources through them is a key aspect of leadership.

At this point it is necessary to distinguish clearly between networks and

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<sup>8</sup>A classic example is Granovetter’s (1973; 1983) analysis of “the strength of weak ties,” weak ties between individuals in different groups (‘bridging ties’) are more important than the strong ties within groups (‘bonding ties’) for social mobilisation.

coalitions. Analytically, the concept ‘network’ does not imply an alignment of purpose, whereas ‘coalitions’ clearly does. Therefore a group of civil society organisations may be linked together in a network, but only become a coalition when they pursue a common goal. As Yashar (1997:15) puts it, “coalitional members, therefore, do not necessarily espouse a uniform ideological position . . . coalitions draw their numerical strength precisely from the fact that they bring together distinct groups.” Furthermore, when we refer to networks, we think largely of the links between individuals, which in turn links together organisations, formally or informally.

In the next sections, I explore to what extent — and how — civil society leaders in South Africa and Uganda have been able to mobilise collective action to address their respective AIDS crises through civil society coalitions and broader AIDS response coalitions that were able to bring together distinct societal groups.

## 2 The political and institutional context of leadership

The clearest and most important insight emerging from the research is that the development of AIDS response coalitions is highly context-dependent. Civil society leaders and elites respond to the opportunities provided, and constraints imposed, by structural factors (like institutional arrangements, political culture and the approach of the state and donors) — or what is often referred to in the social movement literature as the political opportunity structure.<sup>9</sup> As Leftwich and Hogg (2007) argue, economic and social structure and level of development is of great consequence — in particular whether elite negotiations occur within the context of a broad societal consensus on the principles and institutions which govern it (i.e. “robust and legitimised institutions” and “agreed rules of the political game”). Historically defined institutions privilege certain social actors as well as define and mediate the range of interests, distribution of resources, sources of conflict, and range of coalitional opportunities (Yashar, 1997:15).

As pointed out in the introduction, the South African and Ugandan polities differ significantly and presented TAC and TASO with widely divergent opportunity structures. Consequently, TAC and TASO chose very different paths in their response to the AIDS crisis — a primary focus on activism and service pro-

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<sup>9</sup>McAdam (1996:27) identifies four dimensions of political opportunity structure that constitute a relative consensus among authors in the field: “[1] the relative openness or closure of the institutionalized political system; [2] the stability or instability of that broad set of elite alignments that typically undergird a polity; [3] the presence or absence of elite allies; and [4] the state’s capacity and propensity for repression.” See also, for example, Tarrow (1996); McAdam (1996); McAdam et al. (2001).

vision respectively. The choice of the Treatment Action Campaign to focus on political mobilisation and activism – specifically: (1) the Intellectual Property Rights regime that impacts on the prices and availability of antiretroviral drugs and other HIV treatments and (2) government policy with respect to antiretroviral treatment – is clearly a function of the agency of its founders (who formed part of a highly politicised elite of former revolutionaries). But it also reflects a number of contextual factors, including:

- the political space provided by the constitutional arrangements in post-apartheid South Africa (freedom of assembly, freedom of speech, an independent and protected media, independent judiciary, etc.);
- a strong tradition of protest and mobilisation against state power honed during many decades of anti-apartheid struggle, the trade union movement, etc.;
- state policy inspired by AIDS denialism;<sup>10</sup> and
- a highly supportive group of donors who did not shy away from supporting the TAC’s contentious approach.

South Africa’s relative level of development (very high by African standards) and relatively sophisticated healthcare system also meant that sufficient state capacity existed to implement the kinds of interventions the TAC proposed. This meant that it made sense for the movement to focus its efforts on the impediments to greater access to antiretroviral treatment, including the intellectual property rights regime that enabled pharmaceutical manufacturers to charge extremely high prices for ARVs and state policy that was hostile to large-scale antiretroviral therapy.

TASO, on the other hand, was founded in the context of a very weak healthcare system without the capacity to care effectively for the deluge of AIDS patients. The country had just emerged from a long period of economic mismanagement (under the Amin and second Obote regimes) and war that had decimated its infrastructure and economy. In addition, at the time (the late

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<sup>10</sup>‘AIDS denialism’ usually refers to a (sometimes divergent) set of views that run radically counter to the accepted scientific consensus and is not amenable to persuasion by scientific evidence. Typical views held by AIDS denialists include that AIDS does not exist, that AIDS is not caused by a virus, that HIV is a harmless infection and that antiretroviral drugs are “toxic” and harmful. Then-South African president Thabo Mbeki apparently held the view that AIDS is not caused by HIV but rather by poverty and that medical interventions like antiretroviral therapy would therefore be counter-productive. He also apparently believed reports of high HIV prevalence in Africa to be inspired by Western prejudices about Africans’ sexuality and feared that conventional AIDS science was part of a plot by pharmaceutical companies and Western governments to sell ineffective drugs to African countries. See Nattrass (2007) for a detailed examination of AIDS denialism in South Africa.

1980s) life-saving treatment had not yet become available, resulting in a focus on combating stigma and discrimination in order to enable patients to “die with dignity.”<sup>11</sup> The state responded in a highly supportive fashion – providing TASO with facilities at Mulago hospital (and later at hospitals throughout the country) and appointing Noerine Kaleeba to the committee in charge of the AIDS Control Programme (a programme established in 1986 in the Ministry of Health to steer the national AIDS response and which would later be replaced the Uganda AIDS Commission). Noerine Kaleeba explains:

I remember the first meeting I had with [President Museveni]. I said, “Mr President, . . . I would like to do something about this disease. We have a small group set up. . .” I don’t think he listened very much to what I explained about TASO, but he did say [to the head of the AIDS Control Programme], “put that woman on the committee.” So when I look today at many leadership attempts by different people on the HIV front in many countries in Africa, [I realise that] I was in a country where the terrain had been set [for civil society to respond]. I think the government had already made a decision that if someone comes up and wants to do something about HIV that is correct [they should be encouraged]. So we didn’t have to contend with government opposition.<sup>12</sup>

According to Thornton (2008:131), the government of Uganda began to realise in the late 1980s that AIDS was not merely a medical matter that could be dealt with through the health system alone. It started developing an approach that would bring all governmental organs, state-supported institutions (like schools and clinics) and civil society (NGOs, CBOs and FBOs) into a nationally-integrated AIDS response. This became known as the ‘multi-sectoral approach.’

A sense of partnership therefore characterised the relationship between TASO and the Ugandan government from early on. However, over time and as TASO grew in size and influence, disagreements inevitably emerged.<sup>13</sup> Many Ugandan AIDS activists and civil society leaders argue that TASO has failed to play a leadership role in civil society and in particular failed to support efforts to hold government to account.<sup>14</sup> Interviews with senior TASO leaders indicate a general unwillingness to acknowledge conflict with government or serious failures in governmental leadership. At most respondents comment off the record and

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<sup>11</sup>Interview with Peter Ssebanja (TASO Director of Advocacy and founding member).

<sup>12</sup>Interview with Noerine Kaleeba.

<sup>13</sup>Interview with Alex Coutinho (TASO Executive Director: 2001–2006).

<sup>14</sup>Interviews with Milly Katana, Beatrice Were and Aaron Muhinda (Ugandan AIDS activists).

most emphasise the necessity to maintain a good working relationship with the government. This reality does not fit the conventional wisdom about Uganda's efforts against AIDS — described as a multi-sectoral partnership characterised by 'openness' — and requires some reflection.

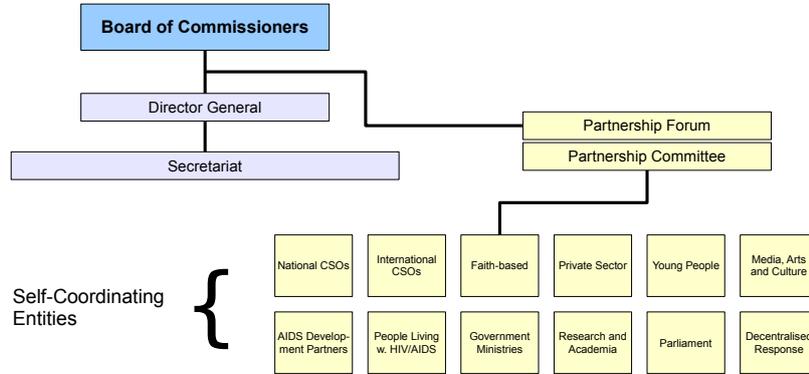
While the leadership provided by and the 'openness' shown by the Ugandan government and of President Museveni are rightly lauded, this reputation is largely based on events of the late 1980s and 1990s. It has been argued, both by respondents in interviews and in some literature (see, for example, Tumushabe, 2006:8), that Museveni's vigorous leadership reflected the very real threat HIV/AIDS in the military represented to the new government's power base (the National Resistance Movement had seized power after defeating Obote's forces in 1986). Furthermore, the new NRM government was heavily reliant on donors (more on their role later) and needed to legitimate itself. Tumushabe (2006:8) has argued that the Ugandan 'success story' on HIV/AIDS became a critical "approval and marketing issue" for the government. In recent years, however, governmental leadership on HIV/AIDS is widely perceived to have declined in quality and vigour. A number of respondents indicate that President Museveni seems to have "withdrawn" from the AIDS response, while others worry about shifts towards less progressive government policy on AIDS. Developments causing widespread concern include, for example, a new hostility to condom promotion and a proposed law that would criminalise (deliberate) HIV transmission. It should therefore be kept in mind that the open and enabling approach of the Ugandan state, was not simply the product of 'good leadership', but to a great extent reflected structural factors like its dependence on donor funding, its lack of capacity to combat HIV/AIDS through established public health infrastructure and new regime's need to consolidate its power.

The reticence of TASO leaders to express criticism and a general weakness on the part of civil society organisations with respect to political advocacy (described by respondents as a "failure to hold government to account") reflects, at least in part, a political culture and institutional arrangements that discourage criticism of the government (and the President in particular). A number of respondents indicated that there are personal and professional risks to being perceived as critical – ranging from exclusion from consultative forums, being cut off from sources of funding and even personal harassment and intimidation. Uganda's transition to multi-party democracy<sup>15</sup> is relatively recent and the protection of civil liberties much weaker than those in South Africa. It is possible that what one sees here is a classic case of a bureaucracy acting in the interests

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<sup>15</sup>Uganda's political system, before the return to multi-party elections after a referendum in 2005, allowed individuals to contest seats but no political parties. It is often referred to as 'non-party democracy' or the 'Movement system'.

Figure 1: Partnership mechanism of the Uganda AIDS Commission



of its own members, rather than towards the ostensible goals of the coalition. Certainly some activists express resentment over the emergence of a class of “parasitic” AIDS professionals who are drawn to the field by the promise of jobs and status.<sup>16</sup>

The custodian of Uganda’s ‘multi-sectoral’ partnership approach and the body charged with coordinating the AIDS response — the Uganda AIDS Commission (UAC) — is widely seen as being under the control of and serving the interests of the Museveni regime. The UAC exercises its coordination role through a Partnership Forum (an annual meeting by a large number of delegates from all sectors) and a Partnership Committee which meets regularly and takes day-to-day decisions, including on resource allocations. The Partnership Committee also acts as the Country Coordinating Mechanism for the Global Fund<sup>17</sup> and controls a joint Civil Society Fund (often referred to as a ‘basket fund’), through which pooled donor contributions are disbursed to civil society organisations. As can be seen in Figure 1, sectors are organised into ‘self-coordinating entities’ that are supposed to develop joint policy positions and present these to the Partnership Committee on behalf of their constituencies. While there are twelve such SCEs, the primary function of the partnership mechanism is to coordinate the work of civil society (international, domestic and faith-based CSOs), donors and government.

<sup>16</sup>Interview with Milly Katana.

<sup>17</sup>The Global Fund to fight AIDS, Tuberculosis and Malaria — set up in 2002 after an initiative by then-UN Secretary General Kofi Annan — is the largest multilateral provider of HIV/AIDS funding (about 20% of international funding). It disburses funds through Country Coordinating Mechanisms in which civil society and governments are supposed to be represented. The current arrangement was the outcome of a consultative process after the Global Fund suspended Uganda’s grants in 2005 after serious mismanagement of funds by the relevant agency in the Ministry of Finance, Planning and Economic Development. Global Fund grants are now dwarfed by those of the US President’s Emergency Plan For AIDS Relief (PEPFAR).

In reality, neither the UAC nor its partnership mechanism is independent of government. All Commissioners are appointed by President Museveni and its Director General (DG) is perceived as highly protective of the President's interests.<sup>18</sup> The UAC is not seen as effectively exercising its coordination function (neither generally nor with respect to civil society).<sup>19</sup> Tellingly, the DG refused to acknowledge any conflict between civil society and the state and denied all problems with the partnership mechanism raised by other respondents.<sup>20</sup>

The recently established Civil Society Fund, operating under the auspices of the Partnership Committee (and supported by many of the donors) is also widely perceived as an attempt to gain control over donor funds for civil society in order to deny resources to organisations critical of the government, effectively turning it into a 'patronage fund'.

Owing to Uganda's level of development, donor agencies ('development partners') are particularly influential in Uganda. More than 90% of all funds spent on AIDS-related programmes are sourced from external sources (Tumushabe, 2006).<sup>21</sup> Their clout has allowed the development partners to push for the inclusive partnership approach and enabling environment created for civil society to participate in the AIDS response. But paradoxically, donors have also inhibited the development of a vocal and independent civil society sector capable of holding the state to account. This is discussed later.

It is important to recognise that the political context and opportunity structures evolve over time and that this may profoundly affect the evolution of movements and coalitions. As the political and institutional landscape evolved in Uganda, attempts were made to close down the space for independent civil society organisations, even as the political system moved to greater openness. The emergence of a generalised AIDS epidemic in South Africa coincided with the radical transformation of a negotiated settlement and democratisation in the early 1990s and came to a head early in Thabo Mbeki's term of office. Despite Mbeki and his Health Minister, Manto Tshabalala-Msimang's relentless hostility to antiretroviral treatment, the South African state never operated as a monolithic entity. Confusion and reversals in AIDS policy resulted from shifting patterns of power and influence within the state, ruling party and civil service.<sup>22</sup> As will be argued later, the 'networks of influence' in which TAC

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<sup>18</sup>Interviews with Milly Katana, Beatrice Were and others.

<sup>19</sup>Interviews with Lilian Mworeko (Country Director: International Community of Women Living with HIV/AIDS), Milly Katana, Beatrice Were and others.

<sup>20</sup>Interview with David Apuuli (Director General: Uganda AIDS Commission).

<sup>21</sup>Reported for 2001/2.

<sup>22</sup>For example, the National Treasury increased the budget for HIV/AIDS programmes substantially in the 2003/2004 budget — apparently with a view to funding a national antiretroviral treatment programme — well before the cabinet had agreed to such a roll-out and while the President and Minister of Health maintained their staunch opposition to such a programme. Even the decision to roll out treatment, taken in August of 2003, is widely seen

activists were embedded extended into state and semi-state institutions, even at the times of greatest hostility. The TAC's relationship with the state veered between conflict and partnership.<sup>23</sup> While TAC has been participating in the South African National AIDS Council (SANAC), a body that is supposed to play a coordinating role similar to that of the UAC, it has largely been a toothless body, treated with disdain by the Minister of Health and not central to policy-making processes.<sup>24</sup> After Mbeki lost a struggle for the leadership of the ruling party and was driven from office in September 2008, Tshabalala-Msimang was replaced by Barbara Hogan, an ANC parliamentarian who had been very sympathetic to TAC over the years. The new Minister even appointed a senior TAC ally (AIDS Law Project attorney Fatima Hassan) as a special advisor, giving the organisation direct access to the Minister.

It is therefore clear that institutional arrangements and historical factors profoundly shape the coalitional opportunities facing civil society actors, including opportunities to forge the state-civil society partnerships that ought to lie at the heart of AIDS response coalitions.

### **3 Coalition-building around AIDS treatment in South Africa and Uganda: from elite networks to AIDS response coalitions**

While the formal and semi-formal networks out of which civil society coalitions are built ('activist networks') are critical to mobilising resources in order to influence policy, dense informal networks consisting out of relationships of trust are also critical in building social movements. Both TAC and TASO drew heavily on pre-existing networks of friends, colleagues and acquaintances to launch the movements, but quickly pulled in like-minded individuals and created links with significant outside actors. The interlinked networks of activists that early TAC leaders had built up prior to TAC's founding, including anti-apartheid, social justice and gay rights activists — and in particular the network of former

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as a "cabinet revolt" (see Natrass, 2007) which the Minister did not support. Despite the provision of treatment by her own department, the Minister continued to express scepticism about ARVs and to support alternative untested "treatments" (see Geffen, 2006).

<sup>23</sup>After years of bitter conflict, a rapprochement between activists and the government occurred in 2006 while the Minister suffered a prolonged illness and the Department of Health was led by the Deputy Minister. In what was described as a "palace coup" by the media, the Deputy Minister (supported by the Deputy President) worked with civil society to formulate and ambitious National Strategic Plan for HIV/AIDS that included policies to which the Minister was known to be hostile. Following her return, however, progress was rapidly reversed and tensions flared up, culminating in the dismissal of the Deputy Minister by Tshabalala-Msimang's patron, President Thabo Mbeki.

<sup>24</sup>Interview with Mark Heywood (TAC National Treasurer 1998-2008, SANAC Deputy Chairperson).

members of the Marxist Workers' Tendency<sup>25</sup> — became an important resource in the building of the TAC, particularly with respect to (1) a shared political outlook, (2) a network of people that could be drawn on to mobilise resources for the new campaign and (3) relationships of trust which could underpin the new TAC's leadership. TASO's founders did not have access to a pre-existing network as geared towards collective action as that of TAC's. Nevertheless, personal friends and acquaintances — especially those formed within the context of Mulago teaching hospital in Kampala — formed the core of the early group (see Ssebanja, 2007). The importance of personal ties in these networks is confirmed by the frequent references by respondents who were involved in the founding of TASO to a “family spirit” that governed their activities. This sense of TASO being a closely-knit family has survived largely in name, but probably contributed significantly to the early development of the organisation.

It is clear from the history of TAC that trust was a critical element of the networks used to build up the movement (Grebe, 2008b:14–15). This is illustrated by an unusually close relationship between Achmat, Heywood and other members of an informal ‘core group’ of leaders and the great degree of deference shown to this group by the rest of the organisation. Similarly, decision-making in the early history of TASO was largely informal and consensual, driven by Kaleeba and a few others.<sup>26</sup> However, as is discussed in the next section, the leadership of the organisations evolved quite differently.

It is notable that the founders of both TAC and TASO were members of educated and well-connected elites. Even though Achmat was not particularly close to the post-apartheid ruling elite in South Africa and Kaleeba was not involved in political and policy issues before founding TASO, both were comfortable in elite circles and capable of engaging in policy debates in a way that most people in the poor and marginalised communities on whose behalf they were acting could never be. This enabled both organisations (esp. through the founders) to mobilise support quickly from other domestic and international elite actors and to build support and influence networks.

While in the UK (where her husband had been diagnosed with AIDS) and some months before TASO was founded, Kaleeba travelled to Geneva and met Jonathan Mann, director of the World Health Organisation's Global Programme on AIDS. She also formed links with UK-based AIDS activists and AIDS service organisations, some of which later supported TASO through training etc.<sup>27</sup>

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<sup>25</sup>The Marxist Workers' Tendency of the African National Congress was a Trotskyist faction operating within the ANC aiming to sway the liberation movement to a path of radical revolutionary activity. Several early TAC leaders (including Zackie Achmat and Mark Heywood, who have been the most influential individuals in the movement) had been members of the MWT during the 1980s and early 1990s.

<sup>26</sup>Interviews with Noerine Kaleeba and Peter Ssebanja.

<sup>27</sup>Interview with Noerine Kaleeba.

Similarly, Achmat, Heywood and other early TAC leaders were able quickly and effectively to supplement pre-existing political networks with new links to international AIDS activists, clinicians, scientists, officials in the Department of Health and other relevant individuals.

The importance of the participation of an educated elite is indicated also by the problems caused by its absence. It is notable that lack of human capacity — specifically the availability of individuals with sufficient education and skills to engage in serious policy debates — are cited frequently by respondents as a reason for a lack of impact by civil society on policy processes.

Both TAC and TASO mobilised civil society alliances and international solidarity networks in building broad coalitions. TASO immediately drew on the links Kaleeba established with AIDS activists in the United Kingdom and pursued support from and partnership with both the government and other local civil society organisations. When TAC was founded, an explicit goal was to build a broad front of progressive organisations pushing for access to antiretroviral therapy. (In fact, TAC was initially conceived as a campaign within the National Association of People Living with HIV/AIDS rather than as an independent organisation.) It relied heavily on resources provided by other CSOs and the founders set out to build relationships with civil society organisations like the churches and trade unions (Grebe, 2008b:19). This approach was clearly rooted in the earlier political experience of leaders like Achmat, who says,

... you need to construct the broadest coalition possible to deal with a particular issue... We understood from the ‘united front’ tactics of Marxism that you constructed the broadest possible alliance under the leadership of the working class, and that’s where I learnt my politics from.<sup>28</sup>

Because many of the impediments to treatment access in South Africa existed at a global level (e.g. the intellectual property rights (IPR) provisions in the international trade regime), TAC leaders pursued international alliances from early on. IPR activists like those of the Consumer Project on Technology and American AIDS activists (like ACT UP Philadelphia and Treatment Action Group<sup>29</sup>) became key allies. TAC has frequently called on its international solidarity network (through ‘Global Days of Action’ etc.) to support its campaigns.

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<sup>28</sup>Interview with Zackie Achmat.

<sup>29</sup>The AIDS Coalition To Unleash Power (ACT UP), started in New York in the mid-1980s, was the most prominent of the early AIDS activist organisations. It faded from view after the mid-1990s (American AIDS activism imploded after its main goal of treatment access had been achieved), but a few chapters like ACT UP Philadelphia were resurrected and remain active (although staffed by different people and with a different focus). However, many currently active activist organisations like Treatment Action Group (TAG) and Health-GAP (Global Access Project) were founded by former ACT UP activists.

Figure 2: Network of influence around the Treatment Action Campaign

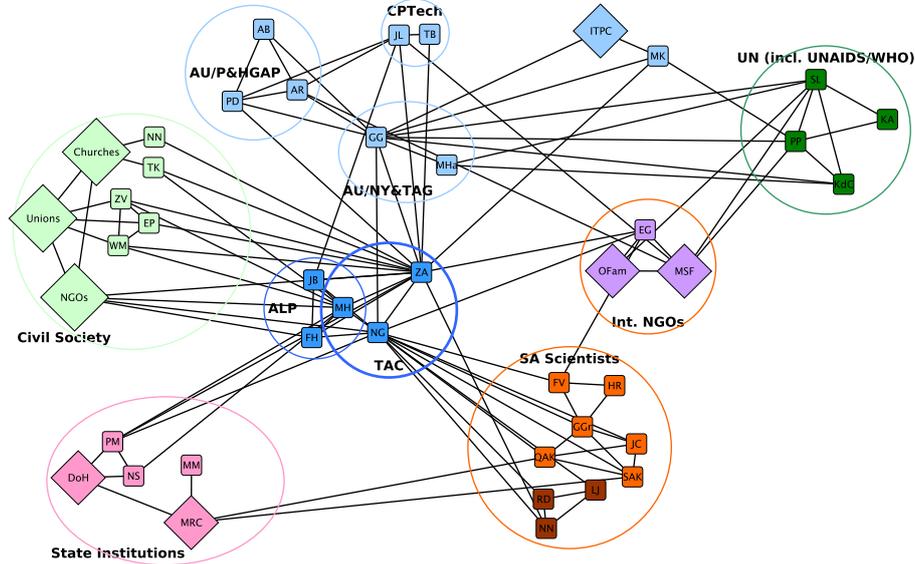


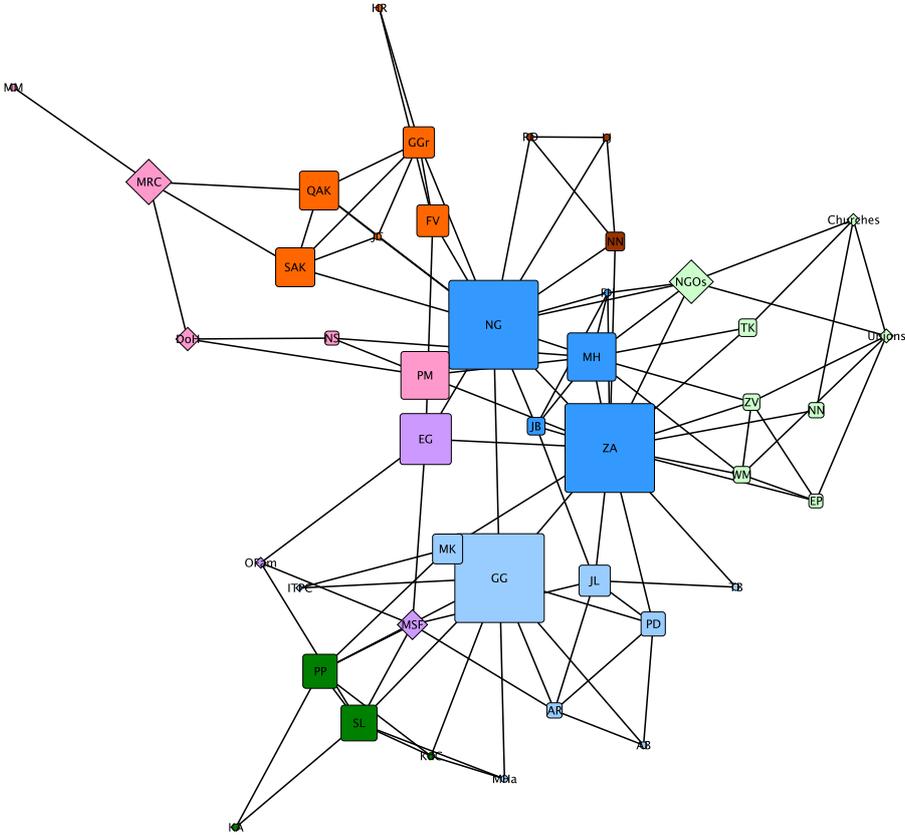
Figure 2 is a simplified network diagram illustrating the most important links in the network around the Treatment Action Campaign. It should be noted that this is not intended to be an exhaustive network analysis but merely to illustrate how networks contribute to coalition-building.<sup>30</sup> For reasons of economy, certain organisations are included as nodes in the network (represented by diamonds in the diagram) even though the real unit of analysis is individuals (represented by rounded squares in the diagram).

Figure 3 shows the same network, but algorithmically visualised using a ‘stress minimisation’ algorithm and uniform link length so as to reveal the position of nodes in the network. Nodes are scaled according to their ‘betweenness centrality,’ which is a rough measure of the importance of a node in ‘broker-ing’ interconnections between disparate network components.<sup>31</sup> It immediately becomes clear that certain individuals, notably Zackie Achmat, Nathan Geffen and Gregg Gonsalves (represented by the nodes labelled ‘ZA’, ‘NG’ and ‘GG’), are unusually important in connecting the various clusters of the network.

<sup>30</sup>The data available to me is not comprehensive enough to allow an exhaustive network analysis. Furthermore, the nodes included in the network diagram reflect my own perceptions and assumptions as well as those of informants, and trying to deduce the relative importance of nodes based on the network structure therefore implies a certain circularity. Nevertheless, the exercise is useful if only for illustrative purposes.

<sup>31</sup>All analysis and visualisation conducted using *Visone* (Brandes and Wagner, 2003).

Figure 3: Network diagram showing 'betweenness centrality' to highlight brokerage roles



## 4 The evolution of movements and coalitions

Movements (and the coalitions that they form or participate in) necessarily evolve over time. Their evolution is shaped by changes in the political context and opportunity structure, by their assessment of their own role and often by the influx of resources (with the formalisation of structures and processes that the latter requires). Some movements – like ACT UP in the United States – never progress beyond an informal (almost anarchist) phase, either because they reach their goals, circumstances render them obsolete or because their internal dynamics drive them to dissolution. Others, however, transform and grow.

Most often successful sustained social movements (like both TAC and TASO) attract donor interest and funding, which creates pressure to formalise and institutionalise their operations. This may create tension between the charismatic and inspirational leadership required to build a social movement and the institutionalised, professional management required for sustainability and efficient service provision.

Both TAC and TASO initially relied principally on relationships of trust and the strong cohesion brought about by charismatic leadership. But as the movements grew, TAC stuck more closely to its roots as an activist organisation, while TASO invested in developing professional management systems. This is reflected in their employment practices, with most TAC staff having started out as volunteers who became integrated in the informal leadership structure, whereas most TASO staff were recruited through formal processes on the basis of professional skills and qualifications. The TASO leadership made an explicit decision early in its history to build formal systems,<sup>32</sup> and donors have also invested substantially in the development of its managerial systems.<sup>33</sup>

Despite the fact that TAC's leadership drew heavily on pre-existing networks, it has become increasingly diversified and a new generation of leaders became part of the web of trust-based relationships by which strategic decision-making is driven. (Heywood acknowledges that the building of a second layer of leadership was a deliberate strategy of the first generation of leaders, because “we realised that TAC needed a local and black leadership, particularly HIV-positive persons,”<sup>34</sup> and it was remarkably successful at doing so. Nevertheless, leadership has in practice remained very informal compared to TASO.

TAC has experienced substantial leadership problems, which it has blamed repeatedly on weak management systems. In Zackie Achmat's last report as Chairperson to the organisation's 2008 National Congress, he stated:

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<sup>32</sup>Interview with Noerine Kaleeba.

<sup>33</sup>Interview with Elise Ayers (Chief of HIV/AIDS, USAID Uganda).

<sup>34</sup>Interview with Mark Heywood.

Historically, TAC leadership and management survived through trust and cohesion that was built through struggle and friendship. The dramatic growth of TAC and the new and complex political tasks, as well as, the day to day permanent crisis of implementation of HIV prevention and treatment required a different approach.

... A skilled political leadership in TAC has managed many of these issues over more than nine years. ... To support skilled political leadership and a motivated membership, TAC requires a professional management and reliable systems that can function in the absence of individuals in leadership or staff. (Achmat, 2008:15–16)

The difficulties arguably result from a hybrid leadership model in which cohesion is maintained both through informal trust-based relationships and formal authority. Despite such difficulties, the TAC has managed to make a relatively successful transition from a small and highly flexible activist grouping, held together by trust and a strong commitment to common goals, to a formal and bureaucratised organisation, which nevertheless retains many characteristics of the former. The hybrid model has served it well, but difficulties are likely to persist as it tries to incorporate the strengths of both ‘activist movement’ and ‘corporate NGO’ leadership models.

TASO has benefited from the strength of its management systems, but has also lost credibility as a social movement and the weakness of its advocacy work has been blamed on it being dominated by professional managers.<sup>35</sup>

## **5 The role of development partners in brokering (or inhibiting) coalitions**

Donors can have tremendous clout in developing countries, particularly in those like Uganda that are heavily dependent on foreign aid. This may provide the opportunity for donors to broker effective coalitions – particularly if civil society is not well-developed or the political institutions/constitutional arrangements inhibit openness and broad participation in policy formulation and implementation. Arguably, the Ugandan state’s lack of capacity in the late 1980s, and its resulting dependence on donors and civil society organisations, is the main reason it opted for an approach of partnership and of creating an enabling environment for civil society. The clout of donors is demonstrated by the resolution of a disagreement between TASO and the government over who was to provide the bulk of antiretroviral therapy, which was decided in TASO’s favour largely

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<sup>35</sup>Interview with Milly Katana.

because this was the preference of the US President's Emergency Plan for AIDS Relief (PEPFAR) – by far the largest HIV/AIDS donor in Uganda.

However, there are also significant risks associated with powerful donors – as confirmed by the research in Uganda. Three main risks can be identified:

- donors may dominate the AIDS response agenda, inhibiting open engagement and inhibiting the ability of domestic actors to build locally appropriate institutions and coalitions;
- ODA may be used to advance a particular ideological agenda driven by the domestic politics of the donor country (and which may consequently be inappropriate);
- donors may be overly concerned with maintaining their partnership with the state, resulting in a failure to support the development of an independent and critical civil society sector.

Arguably all three these risks have been actualised in Uganda. A focus in recent years on antiretroviral treatment to the detriment of prevention interventions largely reflect donor interest in treatment. PEPFAR, which supplies the bulk of HIV/AIDS funding in Uganda, imposes religiously-inspired conditions on recipients that undermine non-abstinence-based prevention programmes (such as condom distribution), programmes that target commercial sex workers and comprehensive reproductive healthcare (that may include termination of pregnancies). Furthermore, donors seem to have discouraged vocal activism and failed to support the more radical civil society organisations. It has also supported a Civil Society Basket Fund that has apparently been used to suppress dissent.

In the case of South Africa, donors have been much less influential in shaping agendas and coalitions, in part because South Africa is not dependent on donor resources for healthcare provision (almost all healthcare for HIV/AIDS is provided by the state from domestic fiscal resources). However, the question of why donors have opted to support a relatively radical movement requires further analysis.

An important general conclusion is that successful AIDS response coalitions do not imply the resolution of all conflict and contestation. In fact attempts at suppressing conflict may harm the long-term effectiveness of coalitions by undermining the ability of civil society actors to influence policy.

## 6 Concluding thoughts

While the difficulties of defining effective AIDS leadership remain, the comparison of civil society involvement in the AIDS response in South Africa and Uganda presented in this paper supports a conception of leadership as the mobilisation of coalitions around AIDS prevention and treatment. Coalitions — alliances of diverse civil society groupings and including parastatal and state institutions as well as the international community — provide a powerful means of overcoming complex collective action problems. Networks of individuals form the basic ‘infrastructure’ of coalitions and AIDS leadership involves building successful coalitions out of such networks.

However, the evidence also shows that political context and opportunity structures (including constitutional and institutional arrangements, political culture, state actions and donor actions) shape elite choices and therefore the development of AIDS response coalitions.

Donors have a potential role in brokering effective coalitions, particularly if civil society is not well-developed or if the political institutions and constitutional arrangements inhibit openness and broad participation in policy formulation and implementation. But if donors fail to support the development of an independent and critical civil society sector (for example by acting to protect the ‘partnership’ between civil society and the state) they may in fact inhibit the formation of effective AIDS response coalitions. Donors therefore need to be mindful of the context-dependence of effective AIDS leadership, and therefore not impose external standards that may have the consequence of inhibiting the formation of locally-appropriate institutions and coalitions.

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## Appendix: List of interviews

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2. Abdool Karim, Salim (Director: CAPRISA): Durban, 9 June 2008.
3. Achmat, Zackie (TAC Deputy General Secretary; TAC Chairperson 1999-2008): Cape Town, 16 June 2007 (conducted by Raja Farah); Cape Town, 30 April 2008; Cape Town, 16 May 2008.
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5. Apuuli, David Kihumuro (Director General: Uganda AIDS Commission): Kampala, 21 October 2008.
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8. Bosch, Deena (TAC founding member): Cape Town, 26 November 2007.
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11. Coutinho, Alex (Executive Director: Infectious Diseases Institute, Makerere University): Kampala, 14 October 2008.
12. Dubula, Vuyiseka (TAC General Secretary): Cape Town, 18 April 2008.

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19. Johnson, Leigh (Centre for Actuarial Research, University of Cape Town): Cape Town, 3 June 2008.
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21. Kaleeba, Noerine (Founder and Patron: TASO): Masaka, 16 October 2008.
22. Kamara, Ronald (HIV/AIDS Advisor: Uganda Catholic Secretariat): Kampala, 28 October 2008.
23. Kana, Buweje (Senior Volunteer: Mbale Centre, TASO): Mbale, 22 October 2008.
24. Katabira, Elly (Professor: Department of Medicine, Makerere University): Kampala, 14 October 2008.
25. Katana, Milly (Project Director: International AIDS Alliance Uganda): Kampala, 24 October 2008.
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31. Ngobi, Charles (Medical Coordinator: Mbale Centre, TASO): Mbale, 22 October 2008.
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