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Remaking Citizenship, Unmaking Marginalization: The Treatment Action Campaign in Post-Apartheid South Africa

Steven Robins and Bettina von Lieres

Résumé

Cet article se concentre sur les formes innovatrices de participation civique, encouragée par le Treatment Action Campaign (TAC), groupe d'activistes du SIDA qui facilite des formes innovatrices de participation civique. Il multiplie ses activités, allant des institutions intermédiaires entre l'état et les pauvres, aux formes de participation plus transitoires, non institutionnelles dans des espaces créés par les marginalisés eux-mêmes. Soutenus par le TAC, les gens se sentent capables d'agir indépendamment de l'état et de le contester. Cet article soutient que, au fur et à mesure que les espaces de participation sont plus souvent modelés par les pauvres eux-mêmes qu'offerts par des acteurs extérieurs, ils mettent en évidence, d'une part les difficultés rencontrées quand on cherche à maintenir de nouvelles stratégies démocratiques de pouvoir, d'autre part, le potentiel de ces politiques en défis, d'une portée considérable, lancés à la marginalisation politique.

Introduction

South Africa's transition to democracy during the 1990s marked an important moment in the development of the global trend towards democratization. For many, South Africa's negotiations to democracy represented the new, post-Cold War age of "deliberative" consensus. Since South Africa's transition was relatively peaceful and successful in ushering in liberal democratic institutions, it has signaled societal integration, as opposed to the kind of cultural and collective disintegration that has come as a result

This article was researched as part of a project prepared for the Development Research Centre on Citizenship, Participation and Accountability (Citizenship DRC), an international research partnership based at the Institute for Development Studies at the University of Sussex, UK and dedicated to exploring the new forms of citizenship needed to make rights real for poor people. The Citizenship DRC's programme emphasizes collaborative work across national, institutional, and interdisciplinary boundaries, adopting an approach that combines research, capacity-building, dissemination, and policy influence. Core funding for the Citizenship DRC is provided by the UK Department for International Development. For more information, please see the Citizenship DRC website: www.ids.ac.uk/drc-citizen.

of the resurgence of ethnic nationalist and cultural separatisms in other parts of the world. But, mostly, South Africa's new democratic politics has been notable for the way in which its liberal framework has been challenged by the consequences of widespread political and economic marginalization, as well as by the claims of traditional leaders. While the legal status of the majority of people is assured, their experience of citizenship is ambiguous. They often remain excluded from effective economic and political participation. If South Africa's new democracy speaks to anything, it is to the uneasy intertwining of democracy and marginalization.

In this broader nexus of democracy and marginalization, new forms of citizen participation are emerging amongst South Africa's poor. While some of these initiatives focus on strengthening existing liberal democratic institutions, others involve forms of participation aimed at creating new interfaces between marginalized people and the institutions that affect their lives, particularly those of the state. While some of these recent forms of participation are created through the intervention of external actors such as donors or the state, others are spaces that poor people create themselves. In some cases, they are challenging existing institutions at the level of the local state. In other cases, they are laying the foundations for new institutions aimed at mediating the relationship between marginalized people and the state. Emerging social movements are taking a leading role in laying the foundations for new, "middle-level" institutions, capable of representing the demands of marginalized people to the state.

This article focuses on the Treatment Action Campaign (TAC), an AIDS activist group that is facilitating innovative forms of citizen participation. It is promoting these activities in multiple sites, ranging from intermediary institutions that serve as an interface between the state and the poor, to more transient, non-institutional forms of participation in spaces created by marginalized people themselves. Supported by TAC, people find themselves able to act independently of the state and to challenge it (Cornwall 2002, 20). Our argument is that as participatory spaces are more often shaped by poor people themselves than offered by outside actors, they show evidence of the difficulties in sustaining new democratic strategies for empowerment, as well as the potential these harbour for far-reaching challenges to political marginalization.

Contesting Multiple Public Spaces: A Case of Globalization from Below

The struggle for access to treatment for people living with HIV/AIDS is also a story about new forms of citizenship (Robins and von Lieres 2004). It is an account of the ways in which new political spaces for citizenship appear to widen as "new democratic experiments meet with and transform older

forms of governance" (Cornwall 2004, 1). The TAC has traversed conventional political boundaries by waging battles in the courts and in the streets simultaneously. While most TAC campaigns are issue-based, often composed of transient interventions characterized more by their intensity than by their durability, these interventions serve to build and sustain the movement's entry into more regularised and institutional spaces.

TAC was established on 10 December 1998, International Human Rights Day, when a group of about fifteen people protested on the steps of St. Georges Cathedral in Cape Town, to demand medical treatment for people living with HIV/AIDS. By the end of the day, the protestors had collected over one thousand signatures calling on the government to develop a treatment plan for all people living with the disease. At that stage, it was generally assumed that anti-AIDS drugs were beyond the reach of all developing countries, condemning ninety percent of the world's HIV-positive population to a painful and inevitable death. By July 2004, an estimated twenty million people had died of AIDS, while more than thirty-eight million had been infected with HIV (*Cape Times* 12 July 2004). Ninety percent of those with HIV and AIDS live in the Third World, of which seventy per cent, an estimated twenty-seven million people, are African. It is estimated that more than 1.5 million South Africans will have died of AIDS-related causes from 2000 to 2005; over 130 000 children will have contracted HIV from their parents each year, and by 2010, two million South African children will have become orphans because their parents will have died of AIDS-related illnesses (Treatment Action Campaign no date). The 2002 UNAIDS report revealed overall HIV/AIDS rates in South Africa at 20.1 percent; the predicted number of deaths among fifteen-to-thirty-four year old South Africans is seventeen times higher than it would be without the disease; one South African in nine — five million people — are already infected or ill with HIV/AIDS; and 24.8 percent of pregnant women tested HIV-positive at government facilities in 2001 (*Cape Times* 3 July 2002).

Soon after its establishment in 1998, TAC, together with the South African government, became embroiled in a lengthy legal battle with international pharmaceutical companies over AIDS drug patents and the importation of generics to treat millions of HIV-positive poor people in developing countries. As a result of highly successful global and national media campaigns, TAC managed to convince international public opinion, and the Pharmaceutical Manufacturers Association (PMA), that their cause was undeniably right and just. In the face of massive public pressure, PMA withdrew its case, having calculated the damage that adverse publicity they were receiving as a result of TAC's stinging accusation that corporate greed was responsible for millions of deaths in Africa. Although the global dimensions of the PMA court case cannot be overestimated, most of TAC's strug-

gles focused on specifically South African issues. These efforts included attempts to hold the Minister of Health accountable for the government's faltering response to the crisis and to protect the independence of institutions such as the Medical Research Council (MRC) and the Medicines Control Council (MCC). These struggles with the Ministry of Health continued in 2004 with Minister Manto Tshabala-Msimang claiming at the Fifteenth International AIDS Conference in Bangkok that a dose of Nevirapine given to a mother and child at the time of delivery produces resistance in some HIV-positive mothers. The Minister blamed TAC for pressuring government through the courts to provide Nevirapine to pregnant mothers. TAC responded by pointing out that civil society organisations had advised government to use a combination of drugs — three for treatment or a dual therapy of Nevirapine and AZT for pregnant mothers. This is but one example of numerous clashes between the Minister of Health and TAC over treatment-related matters.

A second issue that preoccupied TAC and health professional was the "AIDS dissident debate," sparked by President Thabo Mbeki's controversial views on AIDS science. South African and international AIDS dissidents were invited by President Mbeki to join mainstream AIDS scientists on the President's AIDS Advisory Panel, provoking considerable opposition from AIDS activists, the health sector, the media, and the parliamentary opposition. It also became quite clear by the end of the 1990s that President Mbeki's Health Minister was initially unwilling to accept the findings of reports and scientific studies that demonstrated the huge impact and alarming incidence of HIV/AIDS on the South African population, and that concluded that it made both economic and medical sense to provide Nevirapine to HIV-positive mothers as part of a national prevention of mother-to-child-transmission (PMTCT) programme (Treatment Action Campaign n.d.). Economists also produced findings demonstrating that a national AIDS treatment programme would be more cost-effective than simply treating opportunistic infections and thereby burdening an already seriously overstrained public health system.

Drawing on such studies, TAC became highly visible in its challenge to the government's stonewalling on effective AIDS treatment policies. Along with the media, health professionals, and civil society organisations, TAC activists highlighted what was widely perceived to be direct government interference and manipulation of AIDS research findings and the workings of regulatory bodies such as the Medicines Control Council (MCC), the body responsible for the registration of drugs. By drawing attention to these threats to independent medical science in South Africa, TAC was also simultaneously creating the political and discursive space for the emergence of new claims and expressions of health citizenship.

TAC's role in expanding legal spaces for effective citizenship became clear in December 2001, when its legal representatives argued before the High Court of South Africa that the State had a positive obligation, according to section 27(2) of the Constitution, to promote access to health care, and that this constitutionally bound obligation could be extended to AIDS drug treatment.[1] While the thrust of the TAC's argument before the High Court focused on socioeconomic rights, and specifically on citizens' rights to health care, the TAC lawyers raised broader issues relating to questions of scientific authority and expertise. The court was obliged to address the ongoing contestation over the scientific "truth" on AIDS, which raged between the TAC, the trade unions, and health professionals on the one side, and the government and ANC on the other.

TAC's interventions promoted growth in its grassroots support base, helping turn it into a multiclass and multiracial social movement. In addition to occupying new legal spaces, TAC engaged in widely publicised acts of "civil disobedience," which played a central role in providing new visibility and innovative forms of organisation. The charismatic leadership of TAC's founder, Zackie Achmat, became the public face of the movement. Achmat was the key figure in TAC's international campaigns, for example, by illegally bringing generic antiretroviral (ARV) drugs into South Africa. Achmat, who is himself HIV-positive, also increased TAC's international and national profile by refusing to take ARVs until these were freely available in public health facilities in South Africa. The Christopher Moraka Defiance Campaign was perhaps a defining moment in TAC's history. It began in July 2000, after the death of HIV-positive TAC volunteer Christopher Moraka. TAC's spokespersons claimed that the drug fluconazole could have eased his pain and prolonged his life, but the drug was not available within the public health system because it was too expensive. The Moraka Defiance Campaign culminated in the PMA deciding to withdraw its legal challenge to the 1997 Medicines and Related Substances Act, legislation that allowed the South African government to reduce the prices of essential medicines.

TAC activists stress that grassroots mobilization is the key to their success. However, these grassroots campaigns have also been accompanied by transnational advocacy and networking; intensive lobbying with national, provincial, and local government officials; as well as litigation in the Constitutional Court and elsewhere. It would seem that these are complementary modes and sites of activism. Locally based work involved AIDS awareness and prevention programmes, as well as treatment literacy campaigns, in schools, factories, community centres, churches, shebeens (drinking places), and through door-to-door visits in the black townships of the major urban centres. It became clear quite early on that by far the major-

ity of TAC volunteers were working-class township youth and unemployed African women. Many of the women were HIV-positive mothers desperate to access life-saving drugs for themselves and their children, often in contexts where they experience hostility and rejection from their communities, friends, and families. As a TAC organiser noted, it was these unemployed women who had the most time on their hands and were therefore available for recruitment into TAC's campaigns. Perhaps the most important reason for the successes of TAC's grassroots mobilization has been its capacity to provide these poor and unemployed HIV-positive mothers with hope and support.

TAC organised across a broad front that spanned the country's racial and class divisions: working class township youth, students, the unemployed, the trade unions, black and white middle class business professionals, health professionals, scientists, the media, and many other ordinary South African citizens. In this way, TAC was able to open spaces for a remarkable democratic discourse of health citizenship. These interventions helped to give previously powerless people political agency and encouraged women to assert control over their own lives and bodies. In doing so, they challenged traditional patriarchal ideas and practices that conspired to make it difficult for African women to access HIV-testing facilities and prevention of mother-to-child-transmission (PMTCT) programmes (Robins 2004). These strategies also involved challenging widespread beliefs, such as that AIDS was really the work of witchcraft; they confronted the conspiracy of silence around the disease, attacked the AIDS stigma attached to those infected with HIV, and stood up to the discrimination and denial that created obstacles to treatment. HIV treatment clinics, especially the Médicines Sans Frontiers (MSF) and TAC ARV treatment programmes in Khayelitsha, Cape Town and Lusikisiki, Eastern Cape Province, became key sites for these locally situated interventions. TAC, together with MSF, is simultaneously a service provider for people living with AIDS; a social movement aiming to raise political consciousness, leverage access to state resources, and increase the scientific and medical knowledge at the disposal of the HIV-positive poor; and a political reform movement and illness-based special interest group operating within the legal and political system on behalf of its membership and the broader South African population.

In many respects, TRC has drawn on the anti-apartheid movement's highly effective use of the courts to challenge racist state policies. During the apartheid period, legal challenges took place alongside mass protests and attempts to render the townships ungovernable. Geoff Budlender, TAC's lawyer from the Legal Resource Centre, an organisation that was extremely effective in challenging state policies during the apartheid era,

noted that during the course of TAC's mobilization around the court cases against the PMA and government, the boundaries between the courtroom and "the streets" became very porous indeed. Budlender argues that Constitutional Court judges could not but be influenced by public opinion in support of TAC, as well as by the daily press articles and positive television coverage of its demonstrations, press conferences, and acts of civil disobedience. The organisation was also able to achieve extraordinary media visibility and shape public opinion through highly creative networking and media imaging; they were able to produce passion and political drama in the midst of dry and tedious constitutional law wrangling. TAC achieved this result through civic action that transcended race and class, as well as educational and occupational divides.

The grassroots public visibility of TAC, along with South African and international moral pressure, exerted through the media, may have influenced the High Court and Constitutional Court decisions in TAC's favour. Marches, demonstrations, press conferences, petitions, defiance campaigns and the like made permeable the boundary, and interconnections between the courts and the streets, as well as local and global public spheres. They also point to the need to develop strategic and multiple relations with the state. For example, in the Western Cape Province, TAC developed very good relations with senior ANC health officials at local government and provincial levels. It is also believed that TAC enjoyed significant privately expressed support from a number of members of President Mbeki's Cabinet.

TAC has been involved in creating a new post-apartheid politics of strategic engagement, partnership, and negotiation. Its political style can best be described as strategic and critical engagement with "the state": at one point, TAC sided with the government in litigation against "profiteering," international pharmaceutical companies; it then took Pretoria to court for dragging its feet on implementing PMTCT and ARV programmes; and, more recently, it has offered its full support to the government once it decided belatedly to implement treatment programmes. This pragmatism is similar, in certain respects, to the politics of patience, negotiation, and consensus building that have become the trademark of the Indian and South African homeless peoples' federations (Robins 2003). When necessary, however, TAC has not hesitated to use the Constitution to challenge the ANC, which was its principal author.

TAC focuses on the consolidation of its grassroots support base, while simultaneously developing networks within international NGOs, as well as with government officials at local, provincial, and national levels. TAC has also engaged the state by pressing for inclusion in deliberative institutions such as the National Economic Development and Labour Council (NEDLAC), as a means to extend its influence with government, business,

and labour.[2] It is this capacity to develop a situationally framed politics shaped by shifting social and political realities that has allowed TAC to escape the cul-de-sac of binary political logics.

Despite conscious efforts to avoid being seen to be "anti-government," TAC's criticism of President Mbeki's support for AIDS dissidents created dilemmas and difficulties in terms of its grassroots mobilization programmes. By opposing the President's views on AIDS, TAC activists opened themselves to government propaganda that threatened their popular support. They were publicly accused by government apologists of being "unpatriotic," "anti-African," and even salespersons of the international pharmaceutical industry. Despite these attempts to label TAC as an anti-government NGO with an anti-ANC agenda, the organisation developed ways of defending its credibility. It did this through a variety of strategies, including workshops, treatment literacy programmes, and public meetings. Yet the leadership never allowed relations with government to degenerate into a binary opposition of "us" and "them." For example, Zackie Achmat repeatedly reminded South Africans that he, as well as most of the rank-and-file TAC membership, remained a loyal member of the ANC. In addition, TAC's approach has been to confront the state when necessary, but also to look for grounds to praise and support it whenever opportunities presented themselves. When the Mbeki government announced in October 2003 its intention to roll out a national programme to deliver antiretroviral therapies to all those who needed them, TAC immediately offered assistance with implementation.

TAC's locally situated understanding of politics is largely a result of the experiences of TAC leadership, who cut their activist teeth during the anti-apartheid struggles of the 1980s. TAC's grassroots mobilization has been through songs at marches, demonstrations, and funerals; regular press releases and conferences; website information dissemination; television documentaries; and national and international networking. This new politics is a sophisticated refashioning of 1980s anti-apartheid activism, using the courts and the media, as well as local and transnational advocacy networks, along with grassroots mobilization and skilful negotiations with the state. It bears more than a family resemblance to the pragmatic political style of the black labour movement and the anti-apartheid coalition, the United Democratic Front, during the struggles of the 1980s. It also resembles the globally connected new social movements (NSMs) that have emerged in many parts of the world in recent years (Cohen and Rai 2000).

AIDS Treatment

TAC is also engaging the state through its own involvement in state-run institutions. In its attempt to mobilize support, it is increasingly struggling

for the opening up and democratization of state institutions such as schools and clinics. For instance, the TAC-supported MSF AIDS treatment units in Khayelitsha and Lusikisiki are located within state clinics, where they have had a significant impact in breaking through the sociocultural barriers of AIDS denial and stigma. In this sense, TAC and MSF are engaged in attempts to disseminate the politics of rights and health citizenship into the institutional fabric of society. In 2004, during its "Right to Know Campaign," TAC threatened to take the government to court because the Department of Health had failed to publicly release full details of both its national treatment plan and ARV "rollout" timetables and targets. Through such actions, TAC assumed the role of a civic watchdog agency.

The aim of these initiatives has been to transform practices in these institutions and to bring these institutions closer to the people. TAC's regional offices and local branches also work closely with community-based organizations in their area so that they are able to create links with state-run local clinics. The organization trains AIDS councillors and treatment literacy practitioners (TLPs), as well as carrying out audits of clinics and hospitals that are running PMTCT and ARV programmes. TAC's local branches also do a lot of door-to-door mobilization. In August 2002, TAC launched a campaign to have the local clinic in Nyanga, one of the more impoverished sections of Cape Town's townships, opened for five, instead of two, days a week. TAC activists recognize that these local, institutional spaces are not transient, and that they provide important sites for engagement with the local state. The organization is an example of a new social movement that has constructed its own arena of action in multiple spaces. Its strength as a social movement lies in its capacity to mobilize the poor in a variety of spaces, ranging from regularized institutions that serve as an interface between people and governmental authorities of various kinds, to more transient methods such as one-off campaigns aimed at opening up deliberation over policies.

TAC's campaigns have expanded the legitimacy of civil-society-led participation. They have also enlarged deliberation in the public sphere to include new discourses of citizenship. TAC activism shares certain similarities with identity-based illness movements elsewhere in the world (Epstein 1996; Petryna 2002). Concepts such as biological citizenship (Petyna 2002) speak to a range of illness-based movements that have mobilised around nuclear radiation, breast cancer, psychiatric illnesses, and HIV/AIDS. "Lay expertification" (Epstein 1996) and "citizen science" (Irwin 1995) are increasingly used to describe citizen responses to unpredictable and poorly managed health and environmental hazards. These developments are linked to what Ulrich Beck refers to as "world risk society." For Beck, who is writing specifically about the advanced capitalist

countries of the West, citizens have become increasingly sceptical and distrustful of scientists and the scientific findings produced by governments and business. It is within this context that "citizen science" (Irwin 1995), "expertification from below," and the making of biological citizens are taking place.

While the linking of biology and health to identity is certainly not new, what is new are the ways in which biological identities, and the interest groups formed in their name, are emerging in different parts of the world (Petryna 2002, 14). These movements have important implications in terms of extending liberal democratic notions of citizenship. In South Africa, for example, there has been a recent call by public health experts for a "new contract" between provider and client (Coetzee and Schneider 2004). The advocates of this contract suggest that the passive and paternalistic surveillance model of direct observation therapy (DOT) TB treatment is not a viable solution for lifelong ARV treatment. Instead, what is needed, they argue, is a highly motivated, "responsibilised," and knowledgeable client with HIV/AIDS.

Drawing on the successes of MSF treatment programmes and TAC treatment literacy campaigns in Khayelitsha and Lusikisiki, public health professionals have called for the creation of an empowered citizenry with high levels of understanding of AIDS issues reinforced by community advocacy and mobilisation processes that promote the rights of people living with HIV/AIDS. According to an "Editorial" by David Coetzee and Helen Schneider (2004),[3] a "public health revolution" that overcomes this culture of public health paternalism is necessary if ART is to succeed. Clearly, TAC's approach could inspire such a "revolution."

Future challenges for the organization lie in consolidating past gains and "deepening democracy" (Appadurai 2002) among its members and the broader South African society. These challenges are becoming particularly evident as ARV programmes are launched in rural areas characterized by chronic poverty and marginalization, and where there has been little AIDS activism and social mobilization. It is in these large, remote, and underserviced areas, many of them in the former bantustans, that the sociocultural obstacles to AIDS treatment are most pronounced. It is here that TAC's brand of AIDS activism and social mobilization could make the difference between life and death, but may be most difficult to mount and sustain.

Conclusion

This article shows how diverse TAC activities and interventions have contributed to creating new political spaces for engagement at local, national, and global levels. TAC's campaigns cut across institutional and non-institutional spaces and are capable of generating multiple kinds of

relations to the state. As a result of TAC's contestation within multiple sites, ordinary citizens have been able to build their political capabilities for democratic engagement. Through treatment literacy campaigns and training programmes on scientific and medical matters related to HIV/AIDS, TAC has also promoted "expertification from below" or what Petryna (2002) refers to as "biological citizenship." Alongside TAC's effective use of the courts, the Internet, media, e-mail, and transnational advocacy networks, a crucial aspect of TAC's work has been its recruitment of large numbers of mostly young and unemployed black women into its ranks. TAC's interventions in these multiple spaces have allowed its membership to move from the margins to the political center stage in South Africa.

New sites of participation may be those spaces that poor people fashion for themselves (in the case of TAC), or they may be spaces in which they gain a sense of the political and moral legitimacy of their concerns, and of their own power and capabilities. Although these new forms of participation may be short-lived, and may, under certain circumstances, become undemocratic, they nonetheless provide their members with opportunities to engage simultaneously in a variety of participatory spaces that cut across institutional and non-institutional spaces and allow for the articulation of new forms of citizenship from below. These new forms of citizenship and participation — which operate at local, city, regional, and international scales — are changing the political landscape of post-apartheid South Africa. It remains to be seen to what extent these new forms of citizenship will be able to transform entrenched inequalities and marginalization inherited from the apartheid era, and which have worsened over the past decade.

Notes

[1] TAC's argument drew extensively on the Constitutional Court case *Government of the Republic of South Africa and others v. Grootboom and others 2001(1) SA 46 CC.* The South African Constitution is unique in providing for water and housing (along with health care and a clean environment) as basic rights in the Bill of Rights. The *Grootboom* Case was a landmark Constitutional Court judgement made on 4 October 2000 on the question of socioeconomic rights. The ruling reasserted the government's constitutional obligation to take all "reasonable ... measures to achieve the progressive realization of the right to access to housing," including specific steps to cater to the more needy elements in the population. It demonstrated that the courts could enforce compliance with socioeconomic rights enshrined in the South African Constitution. This ruling has set a precedent that potentially opens up the way for challenges to social and economic policies for their failings and omissions (see Isandla Institute Poverty Communique: The Grootboom Case — Landmark Constitutional Judgement on Socio-Economic Rights, 8 March 2001, Volume 3,

No.3).

[2] During the latter half of 2002, TAC, along with its trade union partner, the Congress of South African Trade Unions (COSATU), was involved in lengthy negotiations at the National Economic Development and Labour Council (NEDLAC) in an attempt to arrive at an agreement with government and business to establish a national AIDS treatment programme. The negotiations came to a standstill in early 2003, but, by the end of the year, the government had announced the establishment of a national ARV programme.

[3] Dr. Andrew Boulle of the University of Cape Town Department of Public Health recently drew Steven Robins' attention to the Coetzee and Schneider editorial.

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