Membership-based organisations in constitutional democracies

Lessons from the Treatment Action Campaign

By Barbara Klugman

in conversation with Treatment Action Campaign national and Eastern Cape office-bearers and staff

About the author

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Disclaimer

Although everything has been done to verify timing, sequencing and facts around the Treatment Action Campaign's processes and outcomes, there may be occasional discrepancies as a result of a lack of historical data – particularly on membership and other institutional information but also on the dynamics of certain advocacy processes.

The views and opinions expressed in this publication are those of the author and are not necessarily shared by The Atlantic Philanthropies.

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Acronyms &
abbreviations

AIDS	Acquired immunodeficiency syndrome
ANC	African National Congress
ARV(s)	Antiretroviral (drugs)
ASASA	Advertising Standards Authority of South Africa
BMET	Budget Monitoring and Expenditure Tracking
CAPRISA	Centre for the AIDS Programme of Research in South Africa
CDRA	Community Development Resource Association
CEO	Chief executive officer
COO	Chief operating officer
COSATU	Congress of South African Trade Unions
DENOSA	Democratic Nursing Organisation of South Africa
DoH	Department of Health
DTI	Department of Trade and Industry
EC	Eastern Cape
ECHCAC	Eastern Cape Health Crisis Action Coalition
GGLN	Good Governance Learning Network
Global Fund	Global Fund to Fight AIDS, Tuberculosis and Malaria
HCT	HIV counselling and testing
HIV	Human immunodeficiency virus
HOSPERSA	Health & Other Services Personnel Trade Union of South Africa
HPV	Human papillomavirus
IP	Intellectual property
LAC	Local AIDS Council (the local arm of SANAC)
LGBTI(s)	Lesbian, gay, bisexual, transgender and intersex (people)
M&E	Monitoring and evaluation
MBO	Membership-based organisation
MCC	Medicines Control Council
MDR	Multi-drug resistant
MEC	Member of the Executive Council (cabinet) of provincial government

MMC	Medical male circumcision
MSF	Médecins Sans Frontières (Doctors Without Borders)
NAPWA	National Association of People Living with HIV and AIDS
NGO	Non-governmental organisation
NSP	National strategic plan (on HIV, STIs and TB)
PCR	Policy, communication and research
PLWHA	People living with HIV and AIDS
PMTCT	Prevention of mother-to-child transmission
POWA	People Opposing Women Abuse
PTLP	Prevention, treatment and literacy practitioner
RCT	Randomised clinical trial
RHAP	Rural Health Advocacy Project
S27	Section27
SA	South Africa
SACC	South African Council of Churches
SANAC	South African National AIDS Council
SANDF	South African National Defence Force
SEED	Sustainable Enterprise for Enabling Development
SRHR	Sexual and reproductive health and rights
SSP	Stop Stockouts Project
STI	Sexually transmitted infection
TAC	Treatment Action Campaign
TB	Tuberculosis
UK	United Kingdom
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNFPA	United Nations Population Fund
US	United States of America
WHO	World Health Organization

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Executive summary

This is a story of people who have least power in society holding government to account and supporting government in its efforts to offer services so that people can realise the right to health. It is a story of extraordinary processes and achievements emerging out of grass-roots activism.

In the early years of South Africa's HIV and AIDS crisis – with the dual problems of high costs of treatment and then a denialist government – the focus of the Treatment Action Campaign's (TAC's) activism was on achieving national policy that would realise the rights of all people to treatment. The TAC used mass mobilisation; built branches across seven provinces; gathered and used the best evidence available; engaged the media nationally and internationally; and both engaged with government and litigated against it where necessary – all the time building networks and alliances that constituted a social movement for the right to treatment. Multiple campaigns and wide-ranging alliances won those rights in laws and policies. At that point the challenge became to ensure implementation of laws and policies to deliver access to appropriate treatment in the context of a failing health system, lack of government action

to prevent and treat HIV, quackery, prohibitive patent laws and medicine prices, and continued stigmatisation of people living with HIV and AIDS by the public at large.

Key elements of the Treatment Action Campaign's success

Voice and power from below

The TAC has branches both in urban and rural areas, including those most affected by the failing health system. The TAC's strength is its branches, which work with individuals and communities. It supports individuals in making sense of information – 'knowing the science' – understanding their rights, dealing with internalised stigma that prevents them from being able to take action, and gaining the motivation, confidence and competence to engage individuals and institutions with power in order to claim those rights.

What the TAC cannot resolve locally, it takes to the district. What it cannot resolve at district level, it takes to the province. And what it cannot resolve at provincial level, it turns into national campaigns. This report's story of the Eastern Cape health crisis illustrates just that. Individual TAC

members can be seen responding to requests from community members who are not getting appropriate treatment at the local level. They go back to the clinic to identify the problem – they know the science, and they know the law. They have built relationships with health care providers and managers. But where local clinic decision-makers could not or would not take action, the TAC moved to the district level. When local clinics did not have the correct medicines, TAC pickets, sit-ins and engagement with sub-district managers resolved the problem. When community protests against a local councillor whose office was next door to the Mabandla Clinic led the municipality to close the clinic and the TAC's calls to district managers yielded no results, the TAC engaged provincial decision-makers who resolved the problem.

In this way, the TAC as a membership-based organisation (MBO) makes a significant contribution because its way of working mirrors the health system – with one major difference. Whereas the health system operates from national level downwards, the TAC operates from the individual and local community levels upwards, with ongoing adaptive and innovative strategies for 'community accountability' (Westhorp et al., 2014).

The TAC actively builds relationships with those with power, leveraging those relationships to get problems solved. It builds the capacity of community members to use legally constituted mechanisms of community accountability effectively such as hospital and community clinics as well as local, district, provincial and national AIDS Councils. But the TAC alone cannot make these structures work in the absence of resources to support community participation, so they are frequently not established, or they represent the interests of those with power. Hence beyond these 'invited' spaces, the TAC invents spaces and opportunities to make allies in the push for action, and to engage or push the state to meet its moral and legal obligations.

Attracting and sustaining members and supporters

What attracts and sustains TAC members and supporters? It is voluntary. An MBO works because people feel strengthened by coming together; they gain inspiration during acts of solidarity when they have stood up to power; they gain motivation from their successes; they gain motivation by seeing members living when they thought they would die, and by seeing members, people who are poor and often HIV-positive like themselves, speaking truth to power and achieving significant results. This is their agenda.

Dealing with difficulties within

Changing the social relationships that foster HIV transmission – discrimination on the basis of sexual orientation, gender-based violence, transactional sex driven by desperate poverty, and norms of masculinity that foster misogyny and sexual violence – is exceptionally difficult. Here the terrain is thick with complexity and the answers less straightforward than holding government accountable, because the problems are inside the community and therefore sometimes inside the organisation itself. The process of challenging these is an ongoing struggle at community level and one that TAC members – and particularly those charged with representing women – increasingly seek to address within the TAC, within their communities, and through national policy and government programmes, again forging partnerships to move this agenda.

Partnerships and alliances

Key to the TAC's success is its ability to find and partner with groups that bring different types of expertise and different constituencies on board. For example, when the health system in the Eastern Cape reached a point of utter collapse, the TAC – in concert with partners (including Médecins Sans Frontières, the Rural Doctors Association of Southern Africa, Rural Health Advocacy Project, Southern African HIV Clinicians Society and Section27) who brought the clinical, technical, health care provider and legal expertise to bolster the voice of the TAC's community constituency – initiated a national campaign around 'death and dying in the Eastern Cape', together forming the Eastern Cape Health Crisis Action Coalition and the Stop Stockouts Project which have put the issues on the national agenda of the public and policy-makers. These groups have also pooled resources for these campaigns.

What makes these partnerships work is the high degree of respect between partners despite their different constituencies and different types of power. Indeed, they leverage that power such that between them – each partner using strategies appropriate to its capacities and constituencies – they are able to mobilise diverse resources and influence community members, media, opinion leaders and decision-makers.

A challenge for the TAC is that the broader HIV and AIDS field as well as initiatives focusing on health system failures see the TAC as essential to sustaining their agenda but wish it had more staff in more places and more ways of sustaining its volunteers so that it could be present in more places, fill more gaps, partner in more initiatives and be everywhere that a membership-based constituency needs to be at this time when services are collapsing in some areas. Other social justice groups are also looking to the TAC, in relation to corruption, to xenophobic violence, and so on. This puts tremendous pressure on the TAC even while its funding resource base has declined significantly.

Being politically astute and adaptable

The TAC navigates between engaging and challenging government, operating with a high degree of political sophistication. It has managed to position itself as both an ally and a critic of the ruling party and of government, sometimes at exactly the same moment, sometimes shifting from one to the other. At the time of writing, for example, the TAC was facilitating government capacity to monitor and manage stock-outs in most provinces while it was being vilified by government in another province and hence picketing and litigating there. Significantly, many of those the TAC targets for advocacy, such as doctors and nurses, express appreciation for its role and indeed look to the TAC to speak out when they cannot.

Mobilising and organising

While the TAC is good at mobilising large numbers of the public to come to marches, pickets and the like, it is its ability to organise membership in specific communities into structures which identify and act on local problems and elect leadership that forms the foundation of the TAC's authenticity. Nothing can replace the credibility of organisations that can give voice to issues emerging from the lived reality of individuals.

Sourcing and using evidence

Also key to the TAC's success is the way it sources or generates and uses evidence to ensure its claims are based on the most up-to-date options for people living with HIV and tuberculosis, and to ensure its members are armed with this information. It has also taken advantage of the now universal coverage

of mobile phones in South Africa to enable its members to get and share information to support mobilising, organising and advocacy without costs – using WhatsApp, Facebook and Twitter.

Lessons and challenges for advocates and donors

Advocates or service providers?

One of the challenges that comes with success is that everyone wants something from the TAC.

Non-governmental organisations (NGOs) want to partner with the TAC because of its membership base and representative processes. Yet such groups frequently fear speaking out together with the TAC for fear of losing their government funding. And they seldom bring with them the resources needed to sustain the TAC's organising.

Government, some funders and even other health NGOs think the TAC could and should be doing many more things, including taking on service provider roles because of the scope of dysfunction of the health system. New funders come to the table with resources for the TAC, but they sometimes fail to understand the skeleton of the whole process – that it is embedded in responsiveness to issues emerging in local communities and addressed by local branches in the first instance, and then moved upwards as necessary.

So funders put money in the wrong places by looking to groups like the TAC to become part of service provision – that is, to fulfil government mandates which government itself is not fulfilling, or funding others to do so. Instead of focusing on making the state function and enabling the TAC to play its role as an advocacy group representing health service users, many funders' offers of

resources to the TAC are linked to it participating in service provision.

As the TAC reached the height of its fame because of its huge contribution to achieving the right to treatment, it agreed to play a role in this vision of implementation in which MBOs and NGOs became service providers. From 2008 to 2012, the TAC shifted its focus to 'model districts' as part of the public health paradigm in which interventions are tested in specific places and if they work, they then get rolled out nationally. The TAC's work in these districts intensified, its relationships with those in power strengthened and it learnt a lot about how to successfully advocate and achieve improvements in service delivery.

However, TAC members in branches that were not in model districts felt unsupported and membership dropped radically. In addition, in the model districts people started joining the TAC not because of its mission and values but in the hope of employment, creating competition between members and undermining the sense of the TAC as 'family' and 'home' that had been generated over the previous years. So just at the point when the TAC founder leaders were moving on and the organisation needed to be developing a new institutional culture, it found itself answerable for 'deliverables' against which it had received funds. Whereas its early funders had funded it because of its imagination, innovation and responsiveness, suddenly the TAC had to report on services delivered and it did not have the systems to do so. Just as it began getting to grips with this challenge, the Global Fund to Fight AIDS, Tuberculosis and Malaria, which was a key funder of this approach, failed to put through funds on time, and then cut its funding altogether. This sent shockwaves through the TAC as members lost salaries and stipends, and morale dropped.

In 2012, TAC leadership took stock and decided to move back to its core role of building branches and responsiveness from the local level upwards. It has recommitted to focusing on branches as the base of its effectiveness and has increased its membership. It has continued with its bottom-up organising and national mobilisation, continually making gains at local, provincial and national levels. Illustrative examples in this report show not only the continuing effectiveness of national campaigns but also how at the local level – using the case of the Eastern Cape – the TAC continues to play a critical role in identifying problems, drawing attention to them and seeking solutions at local level, cascading its efforts upwards when local structures cannot resolve them. These illustrate why an MBO is so critical in the current era of 'monitory democracy' (Keane, 2011) where those most affected position themselves to hold government accountable.

Funding social change advocacy

A primary finding of this report is that for funders to support innovative and strategic advocacy for social change, they need to use a trust-based model of accountability and not one based on sanction (Mansbridge, 2014). Instead of being driven by 'indicator blindness' (Patrizi et al., 2013), funders need to find groups that have the values and strategic capacities needed, and then let them read the terrain, shifting strategies as needed rather than being accountable for delivering outcomes they have had to predict in advance despite operating in highly complex systems.

Core funding or general support committed over numbers of years is essential if groups are going to take on and make progress in challenging and addressing intractable issues of inequity and discrimination. The current trend of funders providing money for specific projects but not for staff and administrative costs of such projects is crippling for organisations as it assumes that they have additional funds to cover their institutional sustainability. In addition, project funding gives organisations no capacity to adapt strategies and actions based on shifting opportunities for impact.

Another key lesson that the TAC's story provides for funders, particularly those committed to funding grass-roots, community and membership-based organisations, is that if the purpose of the funding is to influence government or corporate policy and practice, it is essential that there are other capacities available to these grantees – legal capacity, research and analytical capacity, organised constituencies of professionals, and so on. If no other funders are supporting such groups, funders of grass-roots initiatives may need to extend their remit to include them because movements for social change need this mix of capacities.

Funders also need courage. Speaking truth to power can be met with the full force of state power, and donors who seek to support change while fearing groups that appear too political cannot be at the cutting edge.

Above all, however, the desire to turn advocates into service providers misses the reality of contemporary 'monitory democracies' (Keane, 2011) – that multiple forms of monitoring are necessary, both in legally established 'invited' spaces and through spaces invented by civil society groups. Democracy requires dissent (Klugman, 2015).

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Introduction

> "[...] the TAC is one of the biggest and most successful post-apartheid civil society organisations."
>
> *(Madlingozi, 2013, p. 100)*

The Treatment Action Campaign (TAC) is most famous for the way it took pharmaceutical companies, quacks and government to task, forcing the provision of antiretroviral (ARV) treatment for HIV-positive South Africans and thereby saving thousands of people's lives. It did so by building a base of support among people infected or affected by HIV and AIDS, and by creating powerful partnerships – with lawyers and service providers, with researchers and advocacy groups, locally, nationally and internationally.

Having won the right to treatment, the TAC shifted its role to ensuring that people infected with HIV are willing and able to take advantage of treatment, that the social environment supports people in preventing transmission and in living with HIV without stigma, and that necessary high-quality health services are accessible to everyone who needs them.

While this sounds simple enough, the barriers have been and continue to be huge – barriers caused by social prejudice as well as by a failing public health system, requiring remedies of recognition, redistribution and representation (Fraser, 2001).

The purpose of this report

The aim of this report is to contribute towards the efforts of other membership-based organisations (MBOs) and non-governmental organisations (NGOs) who promote social justice, and of the funders who support them.

Besides the TAC's own reports, there are multiple studies of the TAC alone and as part of the broader social movement around HIV (Cullinan & Thom 2009; Friedman, 2010; Grebe 2011; Lawson, 2008). There are books written about the TAC's achievements focusing on its initial goals (Geffen, 2010; Moyle, 2015; Treatment Action Campaign, 2010). In addition, The Atlantic Philanthropies has supported analyses of the relationship between grass-roots movements and public litigation (Budlender et al., 2014; Marcus & Budlender, 2008). The TAC has also had a series of external evaluations (Boulle & Avafia, 2005; Lawson, 2013; Taylor et al., 2015).

This report provides examples of key achievements of the TAC over time to illustrate the mix of strategies it has used nationally and locally, and the sometimes small, sometimes enormous changes these have helped bring about. The report then

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draws out insights and lessons identified by the author in conversation with TAC staff, elected leadership and members, with a focus on the TAC's organising rather than on its litigation or high-profile campaigns that are already well documented.

In sum, this report is neither a history, nor an evaluation of the TAC but rather an effort to distil lessons for the field primarily from the organisational experience of the TAC.

Methodology

The approach to the task of identifying lessons for the field was shaped through two consultation meetings. The first was with the executive committee of the TAC on 4 May 2015, which proposed that I focus on the experience of one province – the Eastern Cape – to make the task manageable. The second was with the TAC Eastern Cape provincial leadership, comprising staff and provincial office-bearers, on 8 May 2015 to ascertain if they thought focusing on the Eastern Cape would be a good idea and what they would like to get out of the project. It was agreed that I should spend time with TAC staff and members in the Eastern Cape in order to capture some of the experience and expertise of those on the ground, even while recognising that the TAC's ways of working differ from branch to branch and from province to province because of differences in

political and cultural contexts, histories and quality of services.

I reviewed all of the TAC's annual reports, its reports to The Atlantic Philanthropies and evaluations, as well as some internal publications and some external commentaries.

I spent three days with TAC staff leadership in the Eastern Cape – Noloyiso Ntamenthlo (provincial coordinator), Vovo Matiso-Gonyela (provincial organiser) and Zukile Madikizela (district organiser Lusikisiki). We reviewed their quarterly reports to the TAC's national council and drew out lessons from the activism, lessons about the monitoring itself, as well as their reflections on their own experience of the TAC. We collectively ran a one-day workshop for the TAC's provincial council in the Eastern Cape where members explored the organisation's strengths and weaknesses and developed a timeline of provincial achievements.

I attended the TAC's national staff and office-bearers' retreat from 10-12 July 2015, facilitated by the Community Development Resource Association (CDRA) as part of its evaluation process, and there had one-on-one informal conversations with participants and with the facilitators regarding issues emerging for this case study. I also interviewed or held informal discussions with staff at the national office, specifically Helen Chorlton (acting COO),

Locunda Karam and Malvin Nhaitayi (resource mobilisation), Lawrence Leseka (monitoring and evaluation – M&E), Marcus Low (policy, communication and research – PCR), Fredalene Booysen (national campaigns manager) and Portia Serote (national women's representative). The first draft of the report was reviewed by Vovo Matiso-Gonyela and Marcus Low, and individual sections were reviewed by other members of staff.

The Treatment Action Campaign at national level and in the Eastern Cape – numbers and reach[1]

The TAC was established on 10 December 1998 – International Human Rights Day. Over time, it expanded from the Western Cape into 229 branches in seven provinces. Figures 1 and 2 overleaf indicate its total membership at 5,884 as of 2014, of whom 2,050 (34.8%) were openly living with HIV. The majority of TAC members are women – 4,576 (77.8%).

The TAC's budget grew from around R216,000[2] (some US$16,600) in 1999 to more than R51 million (approximately US$4 million) in 2008, after which the organisation went through a major financial crisis and downsizing. Its 2014 budget was R36 million (around US$2.8 million).

As of October 2015, the TAC had 20 national members of staff, 27 in provinces and 76 on stipends. The TAC has branches in seven provinces, reaching into urban informal settlements and rural areas in the most impoverished and poorly served parts of the country.

In 2000, TAC member Mandla Majola and Dr Eric Goemaere from Médecins Sans Frontières (MSF) visited the Eastern Cape looking for a rural site at which to set up a clinic. The TAC became active in the Eastern Cape in 2001, and by 2002, it had 17 branches and three members of staff. By 2003, the TAC had established its first office and MSF began to provide ARVs in Lusikisiki, with the TAC having to undo misperceptions about HIV and treatment and address people's suspicions of both groups.

By 2004, the TAC had grown to 49 branches, five members of staff and 1,900 members, jumping to 3,900 members by 2005. As a result of the shift in attention from branches to model districts (an issue discussed later in this report), by 2012, the main Eastern Cape office in East London was down to 388 members, with the TAC having opened a second office in the model district of Lusikisiki.

As of 2014, the TAC had 23 branches with 760 paid-up members (614 women and 146 men) of whom 567 (75%) – 458 women and 109 men – were openly living with HIV. The number of TAC branches (see figure 3 further down) as well as membership is growing in the Eastern Cape, but membership figures for 2015 are still being captured. However, it should be noted that right from its early days, the TAC has mobilised large numbers of supporters – they may not all sign and pay up as members, but they consider themselves part of the TAC nevertheless.

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[1] The information in this section is drawn from the TAC's annual reports, reports from the TAC Eastern Cape to national council, the Eastern Cape workshops with elected and staff leadership conducted for this case study, as well as from the AIDS Law Project history (Moyle, 2015), bits of information provided on request by TAC staff, and comments on the text by Marcus Low (TAC director of policy, communication and research) and Helen Chorlton (TAC acting COO).

[2] R=ZAR, the South African currency. At the time of writing the exchange rate was approximately US$1:ZAR13.

Figure 1: TAC members by province and gender 2014
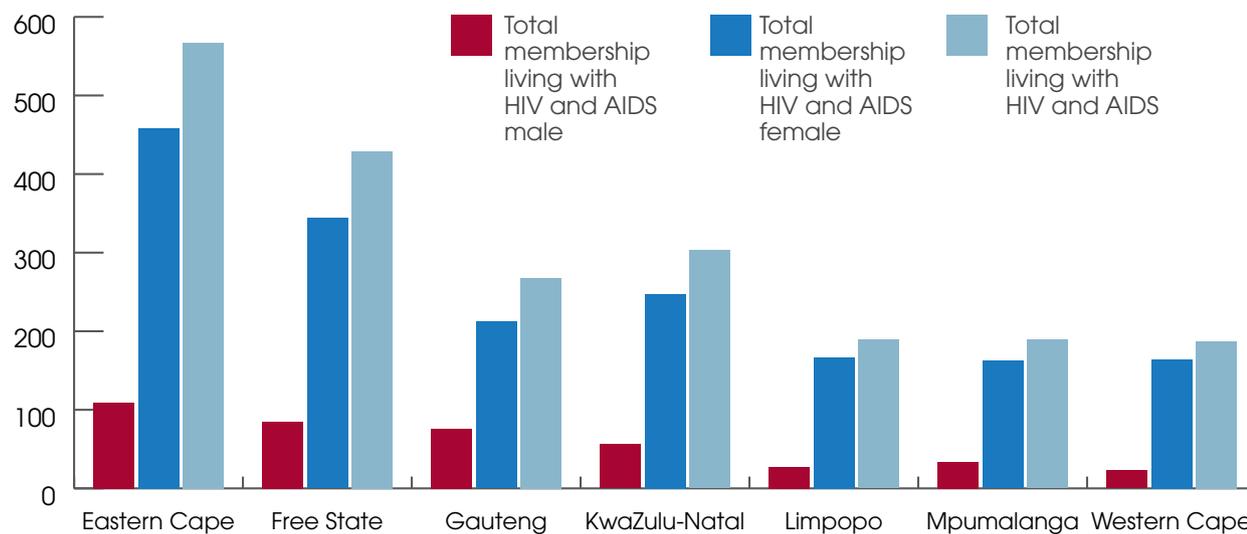
Figure 2: TAC members living with HIV and AIDS by province and gender 2014

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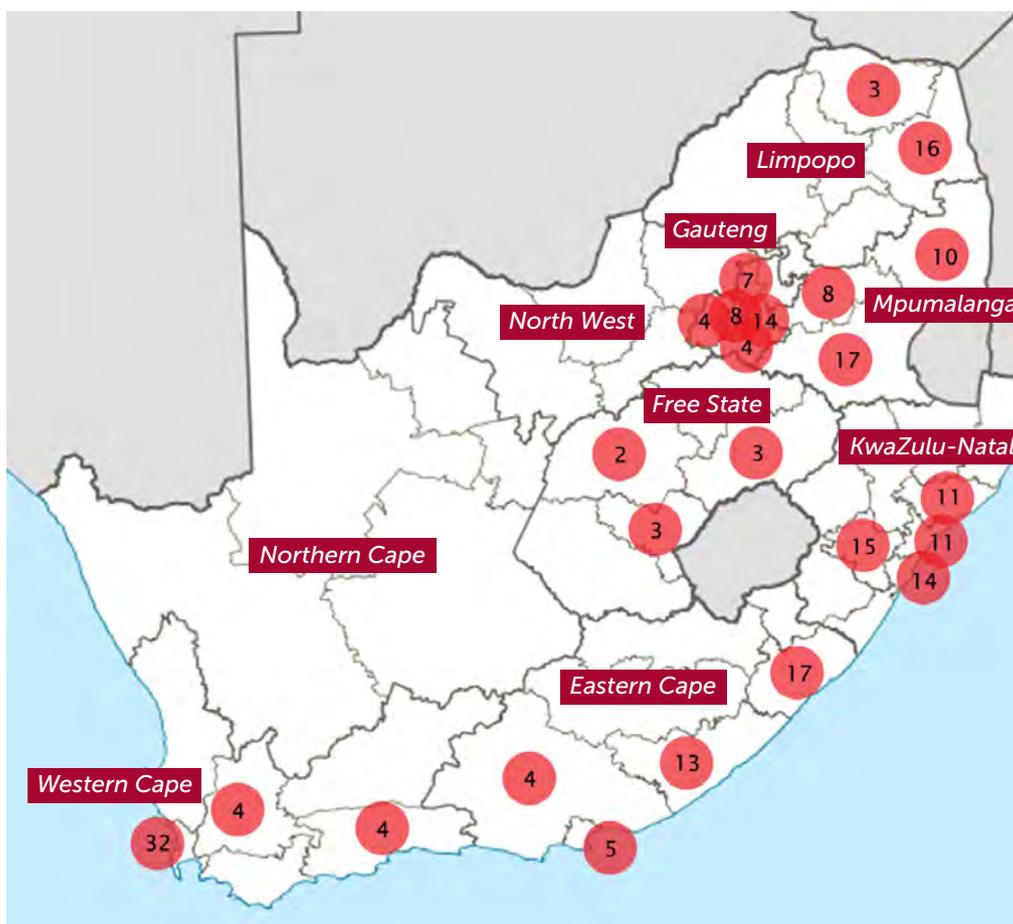
Figure 3: Numbers of TAC branches across South Africa as of October 2015

The Treatment Action Campaign's structure and overall strategy mix

South Africa's political system has a decentralised process of governance where the national level makes policy and allocates the budget; the provincial level interprets policy[3], receives and distributes funds to the district and then local level, which together are responsible for delivery of services.

As an MBO, the TAC makes a significant contribution because its way of working mirrors South Africa's health system, with one major difference. Whereas the health system operates from national level downwards, the TAC operates from the individual and local community levels upwards.

The TAC organises its members in branches, and members elect branch leadership as well as people to represent specific interests such as those of HIV-positive members and those of women members – this is what the TAC terms 'sectors'.

The TAC operates from the individual and local community levels upwards.

[3] Constitutionally, health is a mandate shared between national and provincial levels.
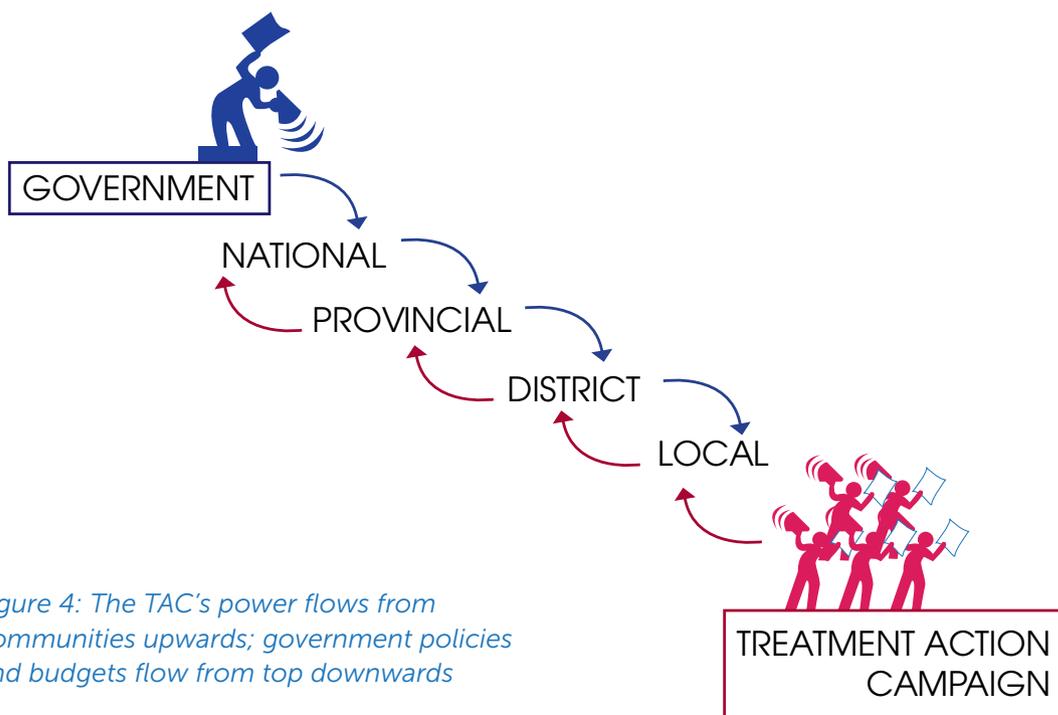
Figure 4: The TAC's power flows from communities upwards; government policies and budgets flow from top downwards

Chairpersons of branches meet together in a provincial TAC council, and chairs of provincial councils form the TAC's national council, which is the TAC's highest political decision-making body. Nationally elected representatives of each sector sit on the TAC's national council too, as do representatives from core TAC partners such as Section27 (S27) and Sonke Gender Justice.

The TAC also has a board which holds fiduciary responsibility. As a result, there is an internal balancing act between the political (elected) leadership structure and the legal structure.

TAC members raise issues relating to community-level challenges at their branch. Branch members and leadership try to resolve these issues at the local level. However, when they cannot do so, they take them to TAC staff or provincial leadership for resolution. Also, if the same issue emerges repeatedly in a number of branches, provincial leadership and staff will bring it to the attention

of national leadership. In this way, as illustrated in figure 4, issues surface in a bottom-up manner and are ultimately shaped into national strategies and campaigns. That said, the policy and research staff of the TAC also play a role in bringing broader field knowledge to members to help them assess their situations and know what kinds of issues and actions are being picked up by HIV research experts and advocacy groups globally.

This report is largely about the TAC and its strategies. It is important to stress from the outset that no particular TAC strategy works in isolation. As explained by Mark Heywood – one of the TAC's founders – the organisation consciously operates a mix of strategies covering popular education, mobilisation, human rights advocacy and, when needed, social justice litigation. Figure 5 shows Heywood's description of the TAC's strategy mix (Heywood, 2015, p. 321).

Social mobilisation through making
political issues moral ones

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Launching campaigns that capture
public imagination and conviction

\+

Empowering communities through
treatment literacy

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Use of law

\+

Effective use of media

Figure 5: The TAC's multiple strategies

2

The Treatment Action Campaign's impact: illustrative chains of actions and outcomes

This chapter[4] illustrates the way the TAC's multiple strategies interact with each other and those of key TAC partners to build knowledge and capacity among those infected and affected by HIV while chipping away at blockages in the private and public sectors. Since the TAC's achievements at a national scale are well documented, the chapter gives but a taste of its national strategies and impacts, focusing then on the community and local dimensions in the Eastern Cape only.

That the TAC is active across seven provinces as well as nationally and internationally is clear. What this chapter explores is the contribution of TAC strategies and actions to actual outcomes – that

is, actions taken by external players (Wilson-Grau & Britt, 2012) which further the goals of treatment access and the right to health locally. It does so by presenting 'outcome chains' which show chronologically TAC actions and how these influenced, directly or indirectly, the actions of external players. Each sub-section begins with a reminder of some of the TAC's key national campaigns and their outcomes. Then, using the Eastern Cape for illustrative purposes, it is shown how national campaigns that make the news are both initiated and also built and bolstered by local actions of TAC members and allies.

It needs to be said that each province has its own political, economic and cultural history, and that the ways of organising, organisational style and priority issues of the TAC differ across provinces. Hence use of the Eastern Cape is not to suggest that it represents the TAC's rural and community experience as a whole but rather – given that the Eastern Cape is one of the most impoverished provinces with one of the least functional public sectors – that the TAC's achievements there give an idea of its contribution nationally.

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[4] The actions and outcomes in this chapter are also drawn from the TAC's annual reports, reports from the TAC Eastern Cape to national council, the Eastern Cape workshops conducted for this case study, as well as from the AIDS Law Project history (Moyle, 2015), bits of information provided on request by TAC staff, and comments from Marcus Low (TAC director of policy, communication and research) and Helen Chorlton (TAC acting COO).

Winning and sustaining the right to treatment

The TAC nationally set itself up to win the right to treatment and has had to continue campaigning on this issue, using litigation, letter writing, pickets, sit-ins and protests continuously. In order to unpack the range of its work, this chapter looks at generic struggles for the right to treatment first, then it goes on to campaigns around access to medicines, around quackery, and around health system capacity.

The TAC's campaigns with partners have included:

- 2003 – Civil Disobedience campaign for a national treatment plan
- 2003 – Stand Up for Our Lives march to parliament with over 10,000 people calling for government to sign a negotiated framework agreement for an HIV/AIDS treatment and prevention plan
- 2004 – the Right to Know campaign for an operational plan and an implementation timetable; the People's Health Summit; and the Joint Civil Society Monitoring Forum
- 2005 – the 2BY6 campaign for 200,000 people to be on treatment by the year 2006
- 2006 – the *TAC Manifesto for Health and Accountable Local Government*, focusing on political parties' commitments before the March 2006 local government elections; and the

National Civil Society Congress
- 2009 – the Resources for Health campaign
- 2013 – A *People's Health Manifesto*, again focusing on the commitment of political parties prior to the May 2014 general elections
- Five campaigns that continued through 2015:
  · Stop the Eastern Cape Health Crisis
  · Stop the Free State Health Crisis
  · Fix the Patent Laws
  · Reducing Cervical Cancer
  · Tuberculosis and Drug-resistant TB (tuberculosis).

Similarly, at provincial level, the TAC and partners have launched local initiatives – in recent years, for example:

- 2012 – in Mpumalanga: a joint programme monitoring health service delivery and the Boycott World AIDS Day march
- 2013 – in the Eastern Cape: the formation of the Eastern Cape Health Crisis Action Coalition (ECHCAC)
- 2013 – in the Western Cape and Gauteng: the Making Local Government Work campaign
- 2014 – in the Free State: the Fire Benny campaign (calling for the dismissal of Free State Health MEC[5] Benny Malakoane)

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[5] Member of the Executive Council (MEC) is the title used for the provincial cabinet members.

- 2015 – also in the Free State: the People's Commission of Inquiry (into the health care system in the province).

At the same time – at local, provincial, national and international levels – the TAC has initiated or participated in many task teams, including the South African National AIDS Council (SANAC[6]) especially in terms of the establishment and monitoring of the national strategic plans (NSPs) on HIV, sexually transmitted infections (STIs) and TB. It has initiated or participated in multiple civil society congresses, notably international and national AIDS conferences, global and national days of action, and so on.

Key outcomes taking forward the right to treatment, to which these campaigns and actions have contributed, include among many others:

- 2001 – the Pretoria High Court ordered government to provide Nevirapine to all pregnant women for the prevention of mother-to-child transmission (PMTCT)
- 2002 – the Constitutional Court denied government appeal; this was later followed by a

PMTCT policy (in February 2008) and by an update of guidelines (in 2009) for HIV-positive pregnant women and people infected with both HIV and TB to initiate treatment at a CD4 count[7] of 350, and for all HIV-positive infants to be provided treatment immediately

- 2003 – cabinet committed to creating a comprehensive treatment plan
- 2005 – a judgment went in favour of the TAC and gave 15 prisoners the right to ARV treatment; this was followed in 2006 by the Durban High Court ordering government to remove restrictions preventing prisoners from accessing treatment; later, in 2013, the Pretoria High Court ruled in favour of the TAC and against the minister of correctional services' appeal
- 2006 – in May, TAC leader Nkhensani Mavasa became the first woman living with HIV to address the UN General Assembly's opening of the Special Session on HIV/AIDS
- 2008 – national 15-minute work force standstill on World AIDS Day

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[6] SANAC was established by government to provide political leadership and build consensus between government, civil society and other stakeholders in South Africa's response to HIV and AIDS. For more on SANAC and the TAC's involvement in the council, see chapter 3 of this report.

[7] A CD4 count is a test that measures the number of CD4 T lymphocytes (CD4 cells) in a blood sample. CD4 cells are a type of white blood cells that play a major role in the immune system. A healthy, HIV-negative adult will have 500-1,200 CD4 cells per mm³ blood. HIV attacks and destroys CD4 cells. A falling CD4 count in an HIV-positive individual therefore indicates that the virus is advancing and that the immune system is weakening.

"I am here to tell you that despite our success story pertaining to the AIDS response, our healthcare system in South Africa is breaking down. I am here to tell you that what the members of communities including TAC are seeing on the ground is a crisis. We are at "code red". The good policies made higher up, often die as soon as they reach provinces. Even worse when they reach local level they've decomposed already.

What we need, more than ever, is strong political leadership to pull our underperforming provinces back into line. We need politicians who are willing to take risks and to say "no" to corruption, to say "no" to deployment of incompetent cadres, to say "no" to underperforming MECs."

Nkhensani Mavasa, TAC chairperson, 9 June 2015 at the
opening plenary of the SA AIDS Conference (Mavasa, 2015)

- 2008 – the North Gauteng High Court found in the case of *South African Security Forces Union and Others v Surgeon General and Others* that policies which excluded people living with HIV and AIDS (PLWHA) from recruitment, external deployment and promotion in the military were unconstitutional and violated the rights of aspirant and serving members of the South African National Defence Force (SANDF) to equality and dignity; later, in 2014, two SANDF members of staff who had been fired were reinstated; also in 2014, in the case of *Dwenga and Others v Surgeon-General of the South African Military Health Services and Others*, the North Gauteng High Court reaffirmed its original finding and denounced the SANDF for violating the court order
- 2010 – adoption of treatment guidelines replacing ARVs Stavudine and Zidovudine with Tenofovir
- 2011 – approval of task-shifting so nurses and not only doctors could initiate ARV therapy
- 2011 – adoption of the *National Strategic Plan on*

HIV, STIs and TB 2012-2016
- 2012 – Western Cape Department of Health (DoH) institutionalised the MSF/TAC adherence club model
- 2012 – in the *Lee v Minister of Correctional Services* case the court found that the Department of Correctional Services was responsible for Dudley Lee contracting TB while in Pollsmoor prison
- 2013 – changing of ARV guidelines to introduce fixed-dose combination treatment
- 2014 – policy change made women living with HIV eligible for pap smears every six months
- 2014 – national implementation of provision of HPV (human papillomavirus) vaccine to girls in school
- 2015 – national government announced its intention to provide condoms in schools
- 2015 – the TAC and Sonke Gender Justice were admitted as friends of the court in a landmark silicosis class action lawsuit (reflecting the broadening of the TAC's focus from HIV and TB to the right to health and health services generally).

Over time, the right to treatment has become inextricably linked to the need for a functioning health system, hence much of the TAC's activism has had to focus on that.

An enabling environment for treatment in the Eastern Cape

Similarly, at local level, TAC members have mobilised to gain and retain the right to treatment, building an active membership and public support through branch newsletters, door-to-door visits and training programmes, including on prevention and treatment literacy.

Since the Civil Disobedience campaign in March 2003, members have used marches to build public awareness against stigma and for treatment. On 12 July 2005, 700 TAC and community members marched from Freedom Square in the centre of Queenstown to the Frontier Hospital demanding 20 more people on ARVs every month as well as the inclusion of people with HIV and TAC representatives on the hospital task team. Police dispersed the TAC demonstrators with tear gas, batons and rubber bullets.

Over time, the TAC built up a layer of treatment and prevention literacy trainers, reaching thousands of people each year – 14,473 women and 6,283 men in 2013 alone. With partners, the TAC has hosted provincial summits and multiple coalitions, including the ECHCAC and the Stop Stockouts Project (SSP). The TAC Eastern Cape has consistently engaged media, who have picked up and given coverage to issues it has raised. It has advocated through multiple strategies – most notably gathering evidence through monitoring health services and through member and community experiences, clinic sit-ins, pickets and marches as well as engagement with policy-makers individually and through existing policy forums.

By way of illustration, in the Eastern Cape these strategies contributed towards the following outcomes:

- 2003 – government committed to rolling out ARVs across the province
- 2004 – increase in the number of accredited ARV sites
- 2005 – the Frontier Hospital removed limits on the number of people it would put onto treatment per month, took on treatment literacy practitioners and invited TAC representatives to join the ARV task team; and four hospitals in the district were accredited as ARV sites.
- 2007 – reduction in the rate of ARV defaulters and the waiting list for ARVs reduced to zero
- 2007 – social support for orphaned boys (linked to the Annie Lennox SING campaign)
- 2008 – shifted perspectives of traditional healers so that they developed a policy for involvement in promoting treatment
- 2009 – an end to HIV-positive people being treated in clinic spaces separate from other patients
- 2009 – government use of mobile trucks to provide services locally so more people could access identity documents and social grants
- 2010 – initiation of youth-friendly clinics giving young people access to services and information in a respectful manner
- 2011 – strategy for the establishment of 'ideal' clinics, including evidence-based demands
- 2011 – Tenofovir approved and made available at primary health care facilities
- 2012 – introduction of demander codes to all clinics in Lusikisiki (to trace the flow of drugs through the system) after ongoing engagement by the TAC and the Centre for Economic Governance and AIDS in Africa in the Budget Monitoring and Expenditure Tracking (BMET) survey

> "[...] if a clinic operational manager or pharmacy assistant is expecting a delivery today and it is not made, they approach me and I do follow-up on their behalf to find the actual cause of the delay in the depot and if need be refer to the provincial Department of Health."
>
> *Ndiphiwe Bekwapi, TAC/SSP*
> *(TAC Eastern Cape, 2015)*

- 2012 – agreement at the Lusikisiki Magwa branch that clinic committee agendas were to be jointly created rather than being set by nurses only
- 2013 – a court order for the opening and continuation of the Village Clinic in Lusikisiki
- 2014 – increased number of parents signing consent forms for their girls to receive the HPV vaccine
- 2014 – gaining additional infrastructure at the clinics in Goso, Malangeni and Quakeni (in response to the BMET survey)
- 2014 – security measures implemented at the Mabandla Clinic in Uitenhage (after nurses were attacked by people protesting against the local councillor, whose office was right next to the clinic)
- 2015 – the MEC for health was replaced after the 2014 general elections (the MEC had refused to meet with the TAC and had denied its concerns; the national DoH dispatched a team to investigate)
- 2015 – reduction in numbers of stock-outs and shortages in clinics and hospitals (as of June 2015) and increased pace in government responses to stock-outs identified by the TAC and the SSP
- 2015 – in March, the South African Human Rights Commission held public hearings on emergency medical services in the Eastern Cape
- 2015 – the Office of Health Standards

Compliance built working relationship with the TAC and the ECHCAC, so that when these two groups identify problems, the office sends inspectors and comes up with recommendations.

Addressing consequences of gender-based violence and discrimination against lesbian, gay, bisexual, transgender and intersex people

From the TAC's early days, it has recognised the relationship between gender-based violence and HIV transmission and treatment, but the murder of TAC member Lorna Mlofana in Khayelitsha, Cape Town, on 13 December 2003 sharpened and shaped the TAC's approach to this interaction (Peacock et al., 2007).

The TAC tends to use calls for justice for victims of gender-based violence as its entry point to engaging communities about this challenge and building their commitment to take action against it. In 2012, the TAC published a guide: *How to respond to rape and other gender-based violence: A guide for survivors and activists*, which supports members' efforts in this regard.

In some provinces where funds have been raised for sexual and reproductive health and rights (SRHR), the TAC uses these resources to deepen its community-based work against gender-based violence, seeing it as intimately implicated in HIV.

[…] at branches we're giving education and attending to individual cases – we have money for branch-specific activities – but at national we don't have funds so we cluster with other groups working on it. (Serote, 2015)

The TAC's main strategy at a national level is to work with allied organisations. With Sonke Gender Justice, People Opposing Women Abuse (POWA) and others it has formed a campaign for a national strategic plan on gender-based violence to raise issues as a collective.

Members in the Eastern Cape have consistently mobilised community members against gender-based violence, through community dialogues and door-to-door mobilisation. They have also advocated to the police and held the police accountable for bringing perpetrators to court. They have engaged staff in the Department of Justice directly, at times through protests, to hold the court system accountable for bringing about justice.

The TAC has not collected stories of how its community-level work to challenge gender-based violence is affecting community practices, so it is impossible to present outcomes in this regard; the information that is available is only on the more measurable features related to its efforts to bring perpetrators to justice – by way of illustration:

- 2007 – rape kits available at the Lusikisiki police station
- 2009 – the OR Tambo mayor supported the building of the Palmerton Child Care Centre for girls who had been abducted through 'ukuthwala' (forced marriage)
- 2012 – shifting the approach of chiefs and communities to people accused of rape from kangaroo courts to working with the police service and using civil courts
- 2012 – rapist of five-year-old child in Mevana convicted and sentenced to 15 years in prison
- 2013 – the Magistrate in Bodweni agreed to investigate ways of addressing the slow pace of rape court cases
- 2014 – a person is charged with rape in Bizana after campaigning by the community.

More recently, the TAC Eastern Cape has initiated a province-wide intervention, engaging community members, traditional leaders and faith-based organisations in dialogues and door-to-door engagements to strengthen community action against discrimination on the basis of sexual orientation or gender expression. It is too early to assess outcomes of this effort, although members feel an impact. At the Eastern Cape consultation for this case study, members argued that a significant outcome for 2015 was that:

LGBTIs [lesbian, gay, bisexual, transgender and intersex people] *are now able to live in communities without fear of prejudice – the community has now accepted* [them] *although we need to do more.* (TAC Eastern Cape, 2015)

"[…] the acceptance of LGBTIs in the community – I feel like dancing like nobody's business."

Notshayina Skepe, community mobiliser at the AIDS Foundation of South Africa and TAC member, Mevana branch, Lusikisiki (TAC Eastern Cape, 2015)

Activism for access to affordable quality medicines

From its beginnings, the TAC – in collaboration with many partners – has taken on private corporations and intellectual property (IP) laws internationally, nationally and locally in order to secure affordable treatment with the most appropriate medicines. It has lodged complaints with the Competition Commission, for example, and made submissions on draft medicine pricing regulations, on IP policy, and on the need to address multi-drug resistant (MDR) TB. It has marched on and made submissions to the various pharmaceutical companies, the Medicines

Control Council (MCC) and parliament, and given presentations at national and international conferences. Expert round-tables have been held and many campaigns on these issues have been mounted, including:

• the launch in November 2011 (on the 10th anniversary of the Doha Declaration on IP and public health) of the Fix the Patent Laws campaign
• after a strident campaign by the TAC and its allies advocating for fixed-dose ARV combinations, government launched its One Pill a Day campaign in April 2013 at the Phedisong Clinic in Ga-Rankuwa north of Pretoria
• the launch in 2015 of the Don't Trade Away Our Health campaign, challenging the efforts of pharmaceutical companies to undermine a forthcoming policy on IP.

All campaigns involved building members' awareness of the issues – with support from the TAC's educational publication Equal Treatment – and mobilising them to take a stand.

This mix of strategies has had many positive outcomes over time, including:

• 2001 – in April, the Pharmaceutical Manufacturers Association of South Africa and 39 multinational drug companies withdrew their case (against government) claiming that the Medicines and Related Substances Control Amendment Act of

1997 hampered their constitutional right to trade

- 2003 – in October, the Competition Commission referred a case against pharmaceutical giants GlaxoSmithKline and Boehringer Ingelheim for their excessive pricing of ARVs to the Competition Tribunal; the companies settled in December by agreeing to issue seven voluntary licenses for other companies in South Africa to produce and/or import, sell and distribute ARVs, and to bring down prices
- 2007 – in April, the MCC registered Tenofovir
- 2007 – the pharmaceutical company MSD (Pty) Ltd (the South African subsidiary of multinational drug company Merck) licensed four generic drug companies in South Africa (two local producers and two local importers) to bring Efavirenz products to the market
- 2009 – in September, the Competition Commission approved a merger between GlaxoSmithKline and Aspen Pharmacare on condition that GlaxoSmithKline grants local generic manufacturers license to manufacture or import Abacavir
- 2009 – the Department of Trade and Industry (DTI) announced the development of an IP policy for South Africa
- 2010 – the DoH updated treatment guidelines in April, replacing Stavudine with Abacavir for infants and children
- 2011 – drug giant Bristol-Myers Squibb expedited

delivery of AmphotericinB to South Africa after it ran out

- 2012 – the DoH included fixed-dose combinations in its December tender for ARV suppliers and started the roll-out in 2013
- 2013 – in September, the DTI published a draft IP policy that included pro-public health content from a TAC and partners memorandum in this regard, and the DTI acknowledged they were also influenced by a TAC and allies picket at the DTI-hosted Africa IP Forum in February
- 2013 – the minister of health announced national roll-out of access to Bedaquiline for treating MDR TB
- 2014 – in January, the minister of health described the 'plot' of the pharmaceutical industry to derail proposed IP reforms as 'genocide' (de Wet, 2014[8]); the executive board of the Innovative Pharmaceutical Association of South Africa, who was implicated, subsequently resigned.

[8] The TAC and others received the information and gave it to Phillip de Wet, journalist at the Mail & Guardian, to investigate and expose.

> "In South Africa, we grant an excessive
> number of patents on medicines […] prices
> remain unaffordable for longer and
> people are dying."
>
> *Nkhensani Mavasa, TAC chairperson*
> *(Rutter & Ribet, 2015)*

Picketing for appropriate drugs branch by branch

At the local level, TAC members pushed for appropriate drugs from clinic to clinic. A review of the August-October 2013 reports from the TAC Eastern Cape to the TAC's national council shows the branches in Bodweni, Mantlaneni, Mevana and Palmerton picketing or conducting sit-ins, as well as engaging ward councillors and a sub-district TB programme manager – actions which resulted in new and better drugs coming onto the market (Eastern Cape TAC, 2013b).

While at national level the TAC pushed for the integration of TB and HIV services and for the provision of Bedaquiline for treatment of TB, at local level the TAC's role has been to identify individuals with MDR TB and build their understanding of the implications of MDR for themselves and their communities. A review of the July 2013-July 2014 reports from the TAC Eastern Cape to the TAC's national council shows many branches[9] identifying MDR individuals who had defaulted on treatment or refused hospitalisation. The TAC counselled them before taking them to health services (Eastern Cape TAC, 2013b; Eastern Cape TAC, 2014).

[9] Bizana, Braelyn, Flagstaff, Magwa, Mantlaneni, Sakhisizwe, Xhurhana, Zanempilo and Zanothando.

Challenging quackery

One of the TAC's ongoing struggles has been against denialism and quackery; the denialism of President Thabo Mbeki and Minister of Health Manto Tshabalala-Msimang from 1999-2008; and the unscrupulous claims of pseudo-scientists, clinicians and religious figures, which continue to this day.

The TAC has built its members' knowledge and motivation to stand up to denialism and quackery as seen in protests, pickets and marches across the country, and in a series of coalitions and campaigns, including the Coalition Against Fraudulent Claims About Medicines. It initiated the website AIDSTruth to combat AIDS denialism, and through which over 80 scientists sent a joint letter to President Mbeki demanding the dismissal of his health minister in September 2006.

With its partners – including S27, the Legal Resources Centre and consumer activists such as Nathan Geffen (GroundUp), Prof Roy Jobson (Rhodes University professor of pharmacology), and Dr Harris Steinman (F.A.C.T.S. – Food & Allergy Consulting & Testing Services) – the TAC has lodged complaints with the Advertising Standards Authority of South Africa (ASASA) against false advertising, taken legal proceedings against the MCC, the minister of health and various 'vitamin-cure' entrepreneurs.

This activism has had multiple successes, including:

• 2005 – ASASA ordered vitamin salesman Matthias Rath to withdraw false advertising on ARVs in South African newspapers

• 2006 – the Cape High Court interdicted Rath from making defamatory and false claims and from slandering the TAC

• 2007 – ASASA ruled against the advert of Zeblon Gwala, who was selling an untested AIDS remedy called uBhejane in KwaZulu-Natal to desperate people for about R300 (approximately US$23) per month

• 2008 – the Cape High Court upheld the Medicines and Related Substances Act 101 of 1965 and established the duty of the state to enforce the scientific governance of medicines. In its judgment, the court ordered the minister of health to take steps to prevent the unauthorised trials of Matthias Rath and other quacks from being conducted in the country, and the court also banned them from advertising their product VitaCell

• 2011 – ASASA ruled that Christ Embassy programmes run on the national TV channel e.tv and making claims to faith-heal were adverts that made unsubstantiated claims and therefore had to be withdrawn

• 2012 – the eThekwini Health Unit mandated a task team to inspect the offices of HIVEX (a company selling over-the-counter 'cures'). The team concluded that HIVEX was making false claims that their products treat HIV. The HIVEX facility in Durban closed its doors, and the HIVEX South Africa website was removed

• 2012 – Solal Technologies lost their case against Kevin Charleston for saying that the claims they made regarding their vitamin and food supplements were pseudo-science.

These national struggles are matched by ongoing actions at local level where, every few months, TAC members hear of individuals peddling untested medications with claims that they cure HIV. Box 1 overleaf illustrates the outcome chain of TAC activism to challenge quackery in the Eastern Cape.

Box 1:

Evidence that hounded a quack out of town – Alice 2013/2014

In late 2013, in the town of Alice in the Nkonkobe municipality, Eastern Cape, the 'prophet' Kuphiso (whose real name is Thandile Madikizela) claimed to be able to cure HIV (as well as epilepsy, diabetes, witchcraft and joblessness) through prayer and through his own holy oil and water, and he advised people to stop taking their ARV medication. Madikizela had informants recruiting people to come to church for prayer in a tent where he conducted services. People gave testimony that they had stopped ARV treatment, were prayed for, and had gone for testing and were HIV-negative. The TAC gave this information to the Daily Dispatch newspaper.

Outcome:
A Daily Dispatch journalist did an investigation and discovered that Madikizela came from the town of Dutywa where he had been accused of some financially fraudulent activities – taking money from a grandmother on the basis that he would pray and double it, but he never paid it back. The Daily Dispatch covered the story.

The TAC found out that Madikizela was using a false identity. Noloyiso Ntamenthlo (TAC provincial coordinator) went to his office in Alice to buy the holy water (for R50 – approximately US$4) and healing oil (for R3,300 – more than US$250) in order to provide proof of Madikizela's activities. He offered her a discount if she joined his organisation, referring her to the Real Vision of Christ Ministries' church service to be held during Easter at Fort Hare University.

The TAC informed the HIV/AIDS desk of the Eastern Cape DoH and the Local AIDS Council (LAC – the local arm of SANAC). In a meeting in May 2014, background information about Madikizela was given, and the evidence Ntamenthlo had found was presented. The LAC, the local service area sub-district manager, ECHCAC, Buffalo City District AIDS Council and the TAC were all present. The TAC asked the LAC to support it in stopping Madikizela's activities.

Outcome:
It was agreed that more information needed to be gathered to engage the Nkonkobe faith-based forum (a sector of the LAC) and the LAC.

We grouped ourselves for different areas, went door to door engaging community members and collecting stories of people who had attended his service or had been sold these products. We compiled this information into a summary report as evidence to back our claims.

The TAC organised a talk show with Fort Hare Radio to do some educational awareness to surrounding community members.

Outcome:
- Fort Hare Radio broadcast a talk show with a community member, the TAC, DoH and the South African Council of Churches (SACC)

- the SACC invited Madikizela to a meeting to present his side of the story

- the pastor did not make himself available. Instead he left Alice.

(TAC, 2014a; TAC Eastern Cape staff leadership, 2015)

Identifying and addressing health system failures

The TAC has two major purposes – one is to build people's knowledge and confidence to get tested and sustain treatment, which includes creating an enabling, stigma-free environment; the other is to ensure that health services function effectively so that people can access appropriate treatment in a context of respect.

Monitoring and challenging medicine stock-outs

The TAC's national campaigns have focused on ensuring that government and the corporate sector make available the most appropriate drugs at affordable prices.

In October 2013, the TAC together with MSF, the Rural Doctors Association of Southern Africa, S27 and the Southern African HIV Clinicians Society established the SSP, which has two processes of surveillance.

The first reaches out through all SSP member organisations to health providers and community service users – including to the formal clinic committees where community members have representatives – providing a system for them to alert the SSP of a stock-out using free mobile phone numbers and WhatsApp. Once alerted, SSP staff follow up at clinic level, escalating queries upwards until they get resolved. These individual alerts provide early warning of potential stock-outs resulting from supplier problems.

The second SSP surveillance process takes the form of a national survey. The SSP uses the evidence gathered through the survey as the basis for advocacy.

At the local level, TAC staff, members and the patients they reach all play a role in identifying stock-outs and alerting the TAC, or the SSP directly, to take action. This is 'monitory democracy' in action (for more, see chapter 3 of this report).

After the SSP published its first survey in 2013, the minister of health took umbrage, denying the extent

of the crisis, attacking the TAC for dishonesty, and placing blame on manufacturers. The SSP, however, found that only 20% of stock-outs reported during the survey were manufacturer-related and that poor management was behind the bulk of stock-outs.

Nevertheless, SSP partners strengthened the survey methodology and also worked hard to build relationships with those responsible for medicines in the DoH. Before publishing findings of the second (2014) survey, the SSP gave government time to review it in advance. By the time of the second survey, the SSP had established an 'escalation protocol' with the DoH, giving it two days to respond to a stock-out query from the SSP at each level – so, when the SSP phones a clinic to verify that a drug is out of stock, and if the clinic confirms, the SSP contacts the district (where the medicines depot for that clinic is based), and it has two days to address the problem; if, however, the district says the problem is at a higher level, then the SSP contacts that level, which then has two days to address the problem. If the problem is not addressed, the SSP goes to the media. Acting Director of the Medical Supplies Depot in Gauteng Dumisani Malele says:

[…] it didn't start on a good footing, but when we set up the escalation protocol, it worked better. It is benefiting government because it is working closely with the very patients we serve – we have a shared interest and we appreciate that. Going forward we need to understand what society is saying and how they think the process can be improved, instead of a top down approach. (Klugman & Jassat, 2015)

Some of the impetus for the SSP came from a crisis at the Mthatha Medicines Depot in the Eastern Cape. Boxes 2 and 3 give examples of the TAC's role in tackling service delivery failures and accessing treatment in the Eastern Cape, and show the importance of its partnership with MSF.

Box 2:

The case of the Mthatha Medicines Depot

The Mthatha Medicines Depot serves over 300 medical facilities with all their medical item needs. In 2012, at any one time, the depot held between R40 million and R50 million (approximately US$3.1 million-US$3.8 million) worth of stock, processing orders worth approximately R30 million (some US$2.3 million) each month.

Due to major problems at the depot (including limited staff, arson in 2011 and an alleged theft of stock in 2012) the principal depot at Port Elizabeth took over many administrative functions. As a result, the depot in Mthatha became more of a logistical hub rather than a fully functional depot.

In September 2012, a national transport strike reduced the amount of orders delivered through Mthatha. In addition, the warehouse had planned a closure for stock counting purposes. Both events meant that the depot received far less deliveries from suppliers than usual, impacting its stock holding capacity.

To make matters worse, in October 2012, depot staff went on a strike, only returning to work more than three weeks later, and eventually 29 members of staff were suspended less than a month before Christmas. This left the depot with only 10 working employees, most of whom were contract staff.

Consequently, supplies were not delivered to the warehouse, orders did not get processed, medical facilities did not get supplies and, ultimately, drugs were not dispensed to patients in need. The number of items issued to medical facilities fell from an average of about 9,000 per month before September 2012, to a mere 1,903 in October. More than 100,000 patients receiving ARV therapy supplied to health facilities by the depot in Mthatha faced an interruption of their treatment (TAC 2013b, p. 2).

Together, MSF, the Rural Health Advocacy Project (RHAP), S27 and the TAC wrote complaints repeatedly to the national and provincial DoH – who did not respond. The TAC then brokered permission from the DoH to intervene.

Outcome:
Ultimately, the DoH agreed that the TAC and MSF could take over the running of the facility as a stopgap measure.

On 7 December 2012, MSF commenced operations at the Mthatha depot with the specific objectives of assisting stock reception, order processing and deliveries to affected medical facilities. Under MSF's guidance and with MSF funding, the TAC deployed more than 20 volunteers to assist in packing and sending medicines to the various clinics and hospitals. These volunteers worked long hours at the depot and other facilities to ensure that the drugs reached patients (Eastern Cape TAC, 2013a).

Outcome:
By 19 December 2012, the backlog of orders had been cleared, and the depot was able to resume its regular functioning. Facilities were once again being supplied with drugs, and thousands of patients received their ARV and TB drugs over the December holidays (Edlmann, 2014; TAC 2013a).

The TAC continued working at the depot, with the support of a few nursing students

Box 2 (continued)

from Walter Sisulu University, until the Eastern Cape DoH appointed more people. Under the guidance of MSF, the TAC established a stock-out monitoring system and hotline, and ensured that people received their medication.

Outcome:

The Eastern Cape DoH appointed 15 people to start employment at the depot in Mthatha on 1 March 2013.

The TAC then assisted in handover back to the Eastern Cape DoH and contributed to a report and recommendations to the national DoH (Lawson, 2013).

Outcome:

• the drug supply chain at the Mthatha depot was restored

• a new initiative, the Drug Supply Monitoring Project, was established by the TAC, MSF and other organisations

• the national DoH initiated planning to abolish the medicines depot system and allow hospital CEOs to order drugs directly from the supplier.

In conclusion, as Lawson notes, "a considerable number of lives were saved and suffering averted by this intervention." (Lawson, 2013, p. 8)

Box 3:

The national Department of Health takes action on the Eastern Cape

The TAC's campaign around the collapse of the Eastern Cape health system, including its publication with S27 of a special report – *Death and dying in the Eastern Cape: An investigation into the collapse of a health system* – the launch of the ECHCAC (with over 25 member organisations) and the 13 September 2013 march to the capital of the Eastern Cape, Bisho, with a memorandum for the provincial health MEC, all spurred the national DoH to intervene. The minister of health sent a ministerial team to the province to:

[f]*ind facts on allegations on state of health services in the Eastern Cape as stated in an article by the TAC, Section 27 and other organisations titled: 'Death and Dying in the Eastern Cape,' an investigation into the collapse of a health system.* (National Department of Health, 2013, p. 5)

Parliament required the department to report on the situation.

Outcome:

• visit of a national ministerial team in September 2013, after which every recommendation made by the team regarding the Holy Cross Hospital in Flagstaff were effected, including suspension of the CEO and the nursing services manager, and disciplinary measures against the hospital administrator

• provincial DoH management has been workshopped on key issues to strengthen hospital management across the province in the following areas:

· governance, including clinical governance
· procurement
· financial management
· human resources management

• the national DoH has arranged for essential equipment to hospitals in the OR Tambo district; equipment has been delivered to the Holy Cross Hospital, for example
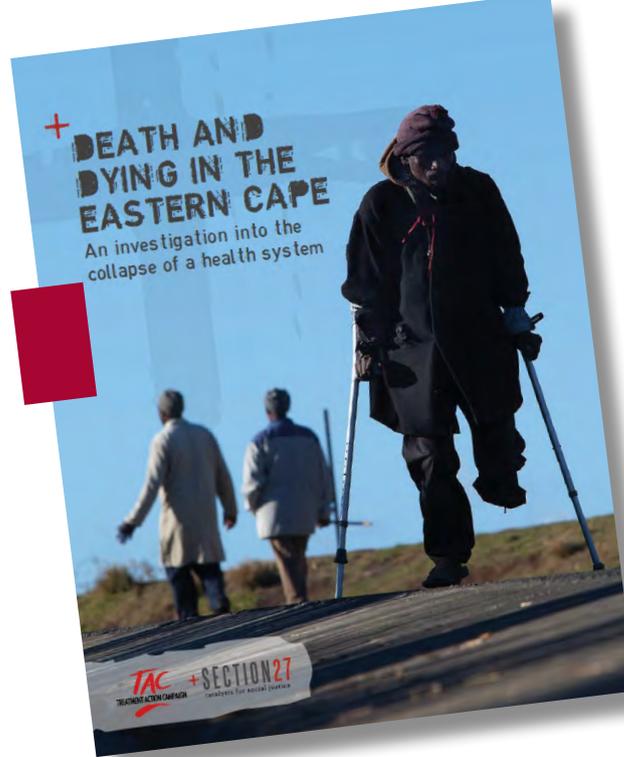
Box 3 (continued)

- the Eastern Cape DoH has appointed a provincial team to work with the district management team to support the OR Tambo district
- the Eastern Cape DoH is also in the process of establishing teams for each of the other districts
- team leaders report to the head of the Eastern Cape DoH and to the health MEC.

(National Department of Health, 2013)

What if there were no Treatment Action Campaign?

It is important to recognise that the TAC was not the only group organising PLWHA. There was already NAPWA (the National Association of People Living with HIV and AIDS) which gave rise to the TAC, although the two later went their separate ways over differences in strategy. In addition, over time, groups with specific constituencies developed, often with TAC members as the instigators – such as the Her Rights Initiative started by Sithembiso Promise Mthembu, or the Positive Women's Network established by Prudence Mabele, both of them TAC members who set up these new organisations out of a concern that more attention needed to be given to the specific needs of women living with HIV. The TAC itself only shifted attention to these issues at a later stage. However, while in most provinces there are some active organisations of PLWHA, none have the TAC's dedicated focus on treatment.

Similarly, there are other groups – organising clinicians, organising youth, organising women – that address HIV, but none bring the mix of a membership base and a 'using-science-to-speak-truth-to-power' approach, coupled with litigation as necessary. It is not possible to say that without the TAC the above changes would not have happened, but the outcome chains set out in this chapter demonstrate the very specific contribution that the TAC has made. They also demonstrate that well after legal victories are won, the need to change minds on the ground, build health system capacities, and to monitor and hold the health system to account, remains. As the health system continues to fail, this need grows.

3

Which factors enable or challenge the Treatment Action Campaign's effectiveness?

This chapter hones in on key elements underpinning the TAC's effectiveness and discusses some of the main challenges the organisation has to navigate. The chapter looks at issues such as the symbiotic relationship between the TAC and its members; the inner workings and internal dynamics of the organisation; its organising and mobilisation strategies; the interplay between accountability, funding, performance and learning; interactions and relations with government, funders and partners; and the role that MBOs like the TAC play in constitutional democracies.

The power of voice

The TAC's working principle is that it addresses the issues pertinent to its members. It is therefore not surprising that 349 (29%) of the 1,212 articles in the publication Equal Treatment – the TAC's primary educational vehicle used by treatment literacy trainers and branch members – include stories of individual women and men as a way of enabling readers to identify with the issues.

The higher proportion of stories about women reflect both the higher proportion of TAC women members and the specific vulnerabilities to HIV faced by women.

Shining a light on stigma – the role of storytelling in social movements

"[...] when the oppressed name their oppression,
they have taken the first step towards self-liberation."

James Baldwin (Suttner, 2015)

Every social movement has at its heart people affected by an issue courageously speaking out and naming their oppression (Suttner, 2015). Speaking out "renders visible a reality that has been previously and deviously hidden to political effect" (Raisborough & Jones, 2007, p. 223). The TAC took being HIV-positive from a shadowy, fearful space into a statement of fact rather than shame, and to a claim for recognition.

The TAC gathered people under this banner to make claims for their rights. Its success was most visibly represented when former President Nelson Mandela wore the TAC's T-shirt, but to this day TAC members and supporters wear the T-shirt as part of their ongoing efforts to eradicate stigma and to remind the public of the issues.

	Number of editions	Stories about women	Stories about men
2005	3	10	4
2006	2	30	14
2007	2	20	4
2008	5	49	61
2009	5	28	6
2010	5	33	18
2011	5	31	12
2012	3	4	10
2013	1	6	1
2014	1	7	1
Totals	**32**	**218**	**131**

Table 1: Numbers of editions and stories about women and men in Equal Treatment 2005-2014[10]

One of the significant dimensions of this process is that it has incorporated not only stigmatisation on the basis of HIV status but also other forms of stigma such as on the basis of sexual orientation and gender expression.

One of the features of the immediate post-apartheid era was that while the anti-apartheid struggles focused particularly on discrimination on the basis of race and class, public opinion leaders, politicians and civil society groups stretched that notion to embrace any form of discrimination, and entrenched this in the Bill of Rights of South Africa's new Constitution. From that moment, even though individuals continued to harbour profound prejudices against particular groups, making these public was no longer acceptable.

The TAC embraced this approach as a matter of faith perhaps, more than as something deeply and continually addressed across the organisation. However, aided in part by the fact that a few of its early leaders were gay, discrimination on the basis of sexual orientation is also explicitly not acceptable in the TAC. This may in turn have been reinforced by the focus of the AIDS establishment on 'vulnerable groups', including sex workers and men who have sex with men.

As seen in the previous chapter, over time, the TAC has reached out to and stood in solidarity with groups organising around such discrimination. The TAC has similarly called for justice for women who have been raped, and it has mobilised against xenophobia. The extent to which the TAC addresses the relationships between these various types of stigma and discrimination on the one side, and HIV prevention, treatment and care on the other is addressed elsewhere in this report.

The TAC took being HIV-positive from a shadowy, fearful space into a statement of fact rather than shame, and to a claim for recognition.

[10] The decrease in the number of editions of Equal Treatment seen in this table is the result of funding shortages in recent years.

What drives people to join and to stay?

Without doubt, in the early days, the levels of stigma and fear of a disease that was killing friends and family brought people to the TAC, which was one of the few visible sites of solidarity and voices demanding a solution.

But what has made them stay? In some cases, people leave when they have the help they need, but others stay because they develop a sense of commitment to others, having themselves gained both hope and health through the organisation. TAC leaders argue that part of this process is the visibility of ordinary members staying alive and vocal – including effectively challenging stigma – that inspires others to join and to stay (Singizi cc, 2011); and older members are the best recruiters because they are living evidence. During focus group discussions for this case study, for example, Vovo Matiso-Gonyela, TAC provincial organiser in the Eastern Cape, described how she has been with the TAC for 12 years and known her HIV status for nine, to which her colleague, Noloyiso Ntamenthlo, added, "so she's a role model to others." (TAC Eastern Cape, 2015)

TAC organisers and members argue that, even today, people are attracted to the TAC because of its brand as an organisation that listens to the experiences and challenges of people on the ground and successfully resolves them (Booysen, 2015). Whereas in the early days it was about the right to treatment in principle, it is now about people's experiences of health system failures. Having a space to share negative experiences with a prospect of doing something about it holds people together. At the same time, the TAC's public mobilisation – pickets, marches, and so on – not only give people a sense of taking action but also strengthen the energy and connectedness between them, the sense of being part of something.

> ## Having a space to share negative experiences with a prospect of doing something about it holds people together.

Another inspiration to members is to see how people like themselves, mostly poor with little education, are able to speak truth to power, including to insist on appropriate medication for themselves (Singizi cc, 2011), and to challenge those in authority to secure their rights. Even the chance to come face to face with those in power can inspire people (Booysen, 2015).

> *People come to TAC for the fact that we are recognised as a source of information, simplified and easily accessible to communities, individuals and families. People come to TAC because of the leadership calibre it has produced over the years.* Vovo Matiso-Gonyela, provincial organiser, TAC Eastern Cape (TAC Eastern Cape staff leadership, 2015)

> *The information that we have, the public speaking – because we were the volunteers not knowing how to speak in the public – the facilitation skills, the advocacy strategies that we have to develop … in a hospital in Lusikisiki I'm telling the nurse something and she doesn't comply and she sees me phoning a district office or Motsoaledi[11] and she is surprised – who is this person?* Zukile Madikizela, TAC district organiser Lusikisiki, Eastern Cape (TAC Eastern Cape, 2015)

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11 Aaron Motsoaledi, minister of health.

An emotional basis for membership: 'TAC is my family, my home'

People of different ages, languages, ethnic groups and religions all tell similar stories about how the TAC saved their lives or those of their families. This experience, and the solidarity they found in the organisation, has given them deep emotional ties to it.

> "TAC became my home [*away*] from home and my support base in my personal tribulations."
>
> *Fikile Boyce, chairperson TAC Eastern Cape (TAC, 2014b)*

I went along with a friend to a meeting that turned out to be a TAC educator teaching the community what HIV is and what its symptoms are. I sat there slowly realising that this is why my one sister had died of meningitis, and the other of TB. We were all advised to get tested. Even though I did not feel sick I walked from there to the clinic for an HIV test. I was positive. My CD4 count was 25 so I went onto treatment there and then. My son is also positive. We take our ARVs together. TAC saved our lives. I have learned a lot about HIV and its treatment. I have become very brave. I share what I know even with people on the train going home. I have taken a stand even in my church. My pastor was preaching against HIV and ARVs but I

knew he was wrong. I worked with him. It took a long time but now he's telling everyone that they should be tested and take treatment when it is needed. Tozi, TAC member, East London (Taylor, 2015)

An activist work culture

TAC members tell stories of empowerment – feeling validated and being able to take action to protect their own health and to advocate for others and for the nation. As an organisation for and about PLWHA, the TAC has always been committed to recruiting PLWHA into membership and leadership. This is a given in the organisation.

However, this does not seem to translate into modelling a healthy life or healthy work-home dynamics. Staff living with HIV work with the same tremendous demands on their time as all others, entailing a workload that extends into evenings and weekends, and a lack of attention to family life and domestic responsibilities.

Despite the huge health challenges of many staff, the TAC promotes the ethos and organisational culture of activist commitment, which is characteristic of South African social movements going back into the apartheid era. Similarly, despite having had a short period in which it provided childcare for some women who brought children to meetings, the TAC has not systematically taken on questions of how

The TAC is a reflection of the broader
society, carrying within it the misogyny
and heterosexual stereotypes as well
as both structural and cultural gender
inequities of society as a whole.

to support activists (whether members, elected leadership or staff, and whether HIV-positive or not) in managing domestic and childcare responsibilities even while playing their activist roles – and particularly when also at times coping with illness.

Gender and power within the Treatment Action Campaign

Internal gender dynamics

The TAC is a reflection of the broader society, carrying within it the misogyny and heterosexual stereotypes as well as both structural and cultural gender inequities of society as a whole (Peacock et al., 2007).

From early on, tensions emerged as some members challenged the TAC's internal culture, which included some cases of sexual harassment. They expressed concerns that issues raised by women were not given adequate attention and that women, despite comprising the majority of members, were not adequately represented in leadership (Leclerc-Madlala, 2008; Stephen, 2009).

These issues were also raised in the TAC's 2005 evaluation, which argued for the need to "mainstream gender into every programme within the organisation" (Boulle & Avafia, 2005, pp. 8 & 67). This all culminated at the TAC's national

congress in 2005 which elected a woman, Sipho Mthathi, as general secretary for the first time; set up a minimum 50% quota for women leadership at all levels; and developed a Women in Leadership Programme (Stephen, 2009). While both men and women supported this process, many of the women who played key roles had been engaged in workshops that provided them the space to articulate the issues and the confidence to take them into the wider TAC forum – including the Gender AIDS Forum in KwaZulu-Natal in 2004 and Gender at Work in early 2005.

The TAC's next general secretary (2008-2014) was also a woman who came up through the ranks – Vuyiseka Dubula – and the increased representation of women in TAC leadership roles has continued.

> […] *internally, Vuyiseka didn't stand for any nonsense – a conscious attempt to make sure our internal culture is progressive and recognises how messed up the culture is that many of our people live in.* (Low, 2015)

However, the vocal internal discussion and explicit efforts to address patriarchal attitudes within the organisation have subsided, and there is still no comprehensive gender policy as proposed in the 2005 evaluation (Boulle & Avafia, 2005), nor is there institutionalised, active and continuous work with staff, elected officials and members challenging

internal power dynamics around gender within the organisation. It is left to individuals – often but not exclusively women – to raise issues as they arise.

There are elected posts of provincial and branch women sector representatives. The TAC's national women's representative, Portia Serote, notes that there is no investment in building the capacities of women sector representatives to effectively engage the institution as a whole (Serote, 2015). This reflects two common features of 'gender mainstreaming' efforts globally – firstly, that those given the task are neither given training for the role, nor resources, and they are not in senior leadership positions organisationally; and secondly, that the issue is depoliticised so that organisations do not address the ways in which gender roles and gendered cultural assumptions shape organisational forms of behaviour and organisational priorities (Sundari Ravindran & Kelkar-Khambete, 2007).

Some argue that there is no longer gender inequity within the TAC or any discrimination; others argue that men stand together, including in criticising women leadership; some argue that in the context of generic disempowerment of women, women in the TAC are often their own worst enemies in failing to support each other in their efforts to address these issues in the organisation. What the commitment to equity in representation has done is to ensure a gender mix of national office-bearers such that, of the current seven national office-bearers, the majority (four) are women.

Implications of gender power dynamics for organisational priorities

At its 2008 national review meeting in Cape Town, despite having some way to go in addressing internal gender dynamics, the TAC decided to embark on a new strategy: advocating for women's rights and fighting gender injustice. National Deputy General Secretary Sindi Blose remembers:

> […] *people said "no, it cuts across all the strategies", but in that meeting I said "no, you need a specific priority." I felt like a donkey in that meeting – like I wasn't moving, but ultimately, especially when Zackie also stood up for it, it was supported.* (Blose, 2015)

One of the reasons given by HIV-positive women for starting alternative or additional organisations has been the TAC's failure to give prominence to the specificities of women's experiences of HIV – particularly their increased vulnerability to cervical cancer, the sterilisation of HIV-positive women and the interactions of hormonal contraceptives with HIV. In some cases, TAC members remain working within the TAC but also work in organisations specifically focusing on these issues (Blose, 2015).

> One of the reasons given by HIV-positive women for starting alternative or additional organisations has been the TAC's failure to give prominence to the specificities of women's experiences of HIV.

At local level, the TAC's treatment literacy training incorporates wide-ranging reproductive health and rights issues that are particular to women's experiences of living with HIV – information about HPV and cervical cancer, what pap smears are and how they work, and encouraging women to ensure they have them; similarly, the TAC provides information on abortion – legal rights and options – at times in entirely neutral terms, at times making clear that this is a woman's choice even though some consider it controversial.

The TAC continually picks up cases of gender-based violence and engages in community dialogues and sensitisation of women and of men on this issue. Programme-specific funds for SRHR activism in the Eastern Cape, Free State and Mpumalanga are currently facilitating this work, as is funding to work on SRHR with young women in Gauteng.

However, the organisation has been unable to bring together trends that emerge from members into national campaigns for action – for example, to address the increased vulnerability of HIV-positive women to cervical cancer with a campaign around building demand for and understanding pap smears; improving access to pap smears as well as the pace at which clinics get and report results to women; and accessing services when abnormalities are identified.

The decision of the TAC's national council in 2014 to make the reduction of cervical cancer one of the TAC's priority campaigns is a big step for the organisation, although it may be that this has come at this particular time because of the arrival of the HPV vaccine – a technical intervention which fits more comfortably into the repertoire of the TAC's claims than issues which require social transformation, challenging women's structural inequality and promoting their reproductive rights.

Unfortunately, however, there has not been enough funding to really move the campaign forward at national level.

> […] *it's never going to go away – the link to HIV is there … where provinces have funds and can do this they do, sensitising women and sensitising men – it's not off our radar, but the lack of funding prevents us from coordinating nationally.* (Booysen, 2015)

This begs questions as to national TAC priorities, in particular whether women wield proportionate power within the organisation. This is a concern not only with regard to cervical cancer but similarly to the TAC's choice to focus predominantly on only one of the PMTCT strategies – prevention of transmission from HIV-positive women to their infants – and not also on prevention of infection among young people and pregnant women, and prevention of unintended pregnancies among HIV-positive women, among others. These latter dimensions have received less funding and less attention internationally (Eyakuze et al., 2008) and in South Africa, with the AIDS establishment consistently separating HIV prevention from the issue of women and men's reproductive intentions (Stevens, 2008).

"[...] more than ten years after their inception, PMTCT programs still do not successfully ensure the adequate treatment, care and support of HIV-infected women [...] the rights and needs of the pregnant woman have in practice become secondary to the overall goal of reducing transmission to the infant."
(Eyakuze et al., 2008, pp. 33 & 34)

This debate surfaced most notably during the court case on PMTCT where the TAC's legal representatives chose to emphasise "the irrationality of the state in limiting access, and the social right of access to health care", missing an opportunity to "develop the idea of women as agents and set out an expansive notion of reproductive choice." (Albertyn & Meer, 2008, pp. 47 & 44, respectively)

Debates between TAC leadership and women's reproductive rights advocates (within and outside of the TAC) were at times vitriolic, in particular when reproductive rights advocates questioned the implications of calling for PMTCT without calling for treatment for the mother, or indeed the father, as TAC National Deputy General Secretary Sindi Blose notes:

[...] the rationale was that the treatment access campaign was for all, and the discussion was 'we can't fight for women only – if you fight for some then you're marginalising women who are not having children, and you are marginalising men'. TAC could have been calling for a broader 'parent to child' approach, but there was a sense that fathers aren't relevant – the understanding of the patriarchal system and gendered context was poor – the father wasn't considered to be responsible in any way. It was a missed opportunity in that period. (Blose, 2015)

Similarly, while issues of contraception and abortion are present in among the TAC's publications and treatment literacy initiatives, they do not feature high in its campaign priorities despite HIV-positive women finding themselves subject to abuse by family members and health care providers, both for choosing to have abortions and for choosing to get pregnant or continue a pregnancy – including in some cases being sterilised without their knowledge (Human Sciences Research Council, 2015; Koka, 2015).

Feminist activists and writers recognise that part of the problem is that unlike the well-organised AIDS movement, there is a general weakness or absence of a women's and reproductive rights movement actively engaging HIV activists – including the TAC – in order to support those concerned with these

issues and build their confidence to take them up internally (Albertyn & Meer, 2008; Klugman, 2011; Leclerc-Madlala 2008), including with evidence of what sorts of interventions are likely to be most effective.

Scientific knowledge grounding action

'Treatment literacy' and later 'prevention and treatment literacy' has been the basis of the TAC's organising strategy. Whether going door to door talking to people in their own homes or running discussions in clinic waiting rooms, at schools or on sports fields, the TAC's point of pride is that many of its members know more about what they call 'the science of HIV' than do nurses, health policy-makers or the public. Indeed, health care providers often join the TAC in order to keep informed (Booysen, 2015).

The TAC's publication Equal Treatment plays a key role in keeping members up to date. Between 2005 and 2014, the TAC produced 32 editions of Equal Treatment (refer table 1 above) and each edition gives readers both technical information and its application to prevention, treatment and advocacy. Each edition also carries stories of the lived experiences of individuals in addressing the issues covered in the articles. Tables 2 and 3 overleaf indicate major themes and key issues covered in

Equal Treatment, in order of frequency/numbers of articles.

From 2013, Equal Treatment was somewhat overtaken by the TAC's joint publication with S27, the NSP Review[12], reflecting greater emphasis in the TAC's programming towards monitoring implementation, as well as a shortage of resources for publications focused on membership and community education. Some additional publications have dealt with member education (such as on gender-based violence), others with public and political pressure (such as the crisis in the Eastern Cape) – a full publications listing for 2010-2015 can be seen in table 4 further down.

An effective distribution and knowledge translation strategy

Until 2009, the TAC printed and distributed 70,000 English copies of each edition of Equal Treatment – at which point (based on an evaluation recommendation) it scaled down to 55,000 copies per edition, divided between English, isiXhosa, isiZulu and Xitsonga. As the numbers indicate, the outreach goes far beyond the TAC's own membership, to community members, partners, health care providers, managers and policy-makers in government departments at national,

[12] NSP being the national strategic plan (on HIV, STIs and TB).

Theme	Number of articles
Treatment	234
Prevention	168
Advocacy	145
Health systems	118
Research	47
Health service implementation	32
TAC internal issues	30
Total	**774**

Table 2: Themes and numbers of articles in Equal Treatment 2005-2014

	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	Totals
HIV	21	44	24	18	36	44	28	20	6	5	**246**
Health systems	7	13	2	5	11	3	14	3		3	**61**
TB	3	1	4	22	2	3	12	1	1		**49**
Violence	1	4	1	8	9	4	2	2	1		**32**
Human rights		7		6	5	9	3				**30**
Sexual & reproductive health		5	2	4		3	1	1			**16**
Migration				12		2	1				**15**
Other	1	2	1	3	4	2					**13**
Social grants				1	7	2					**10**
HPV			2	1	2	1				1	**7**
Mental health		1				5					**6**
Quackery	3	1		1							**5**
Totals	**36**	**78**	**36**	**81**	**76**	**78**	**61**	**27**	**8**	**9**	**490**

Table 3: Key issues and numbers of articles in Equal Treatment 2005-2014

	Equal Treatment	NSP Review	Other
2010	• HIV & happiness • The struggle for treatment continues • Getting serious about HIV prevention • Making human rights a reality • Living with HIV		• Fighting for our lives: The history of the Treatment Action Campaign 1998-2010
2011	• Bridge the divide • Drug resistance • Who does the caring? • TB can be cured • Fix the laws – save our lives!		
2012	• Learn about HIV • HIV and TB in the future • HIV and babies	• Time for a TB revolution: A historic meeting maps the way forward • Better budgets for better health • Change at the top... change on the ground? • Human rights and the law	• How to respond to rape and other gender-based violence: A guide for survivors and activists
2013	• It is getting easier	• Our failing provincial health systems • Helping teens fight HIV • TB and the NSP • The NSP: Do we know what's happening? • HIV positive – is South Africa winning?	• Death and dying in the Eastern Cape: An investigation into the collapse of a health system • Reforming South Africa's patent laws to promote access to medicines: An activist guide to the Fix the Patent Laws campaign • Stock outs in South Africa: A national crisis
2014	• Pain in the public sector	• A frank look at South Africa's response to drug-resistant TB • The National Health Laboratory Service: A looming disaster • Ten years of ARVs in South Africa: Great victories – but not the end of the battle (special edition)	
2015		• South Africa's AIDS & TB response: Code red?	

Table 4: TAC publications 2010-2015

FIGHTING
1998–2010
FOR
OUR LIVES
The history of the
Treatment Action Campaign
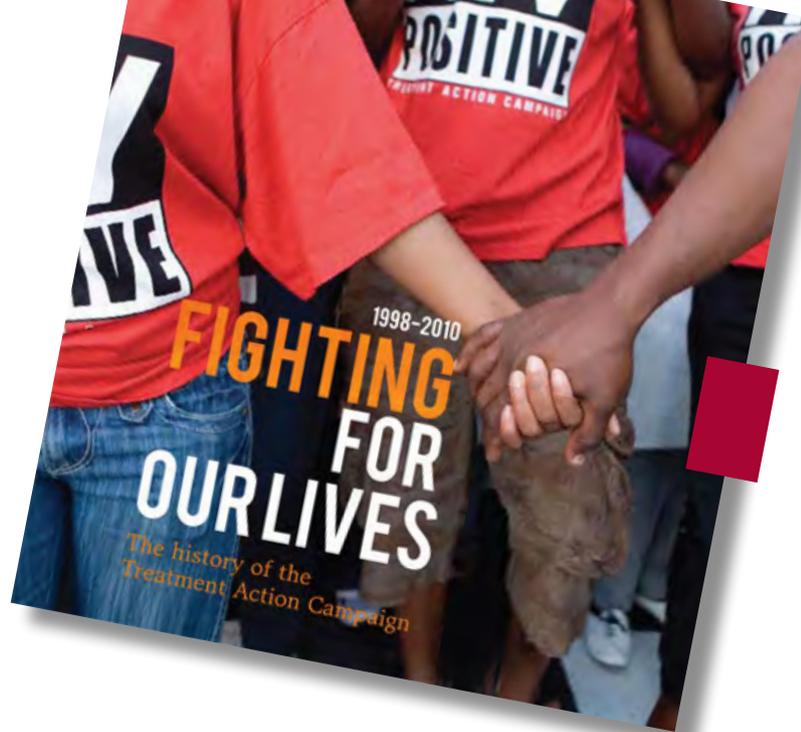
provincial and local levels, as well as to libraries and academics. Some TAC branches have reading groups where Equal Treatment is used routinely to strengthen members' capacities.

But knowledge is not enough. Multiple studies show that gaining new information does not alone lead people to change their behaviour. People also need to experience a shift in motivation so that they want to take action, and they need to have or to gain the skills needed to effectively take action (Coffman, 2011; Lynn et al., 2013; World Health Organization, 2015). The TAC has brought together building people's knowledge of the science with the idea of the right to health as the motivating fire. Not only do they know how the disease can be prevented and treated, but they also believe in the rights of all people to have quality services. Further, the TAC builds people's confidence and skills to protect their own health – using condoms, getting tested, going for treatment, remaining on treatment – and to take action to hold government responsible for service delivery, be it the judicial system for bringing perpetrators of sexual violence to book or the public health services for treating people with dignity and providing appropriate medications.

The TAC has made me politically strong. When I see something wrong, I see it's time to act. I ask the district organizer to help me push things, to help people get their human rights. If someone

was looking well but has a third stage illness, and was denied a grant, I could fight for them. Even I demanded acyclovir from the clinic in Bisho in June. I was caught by high fever. I developed herpes around my mouth. They took me to Bisho hospital and they gave me anti-fungal tablets. I said it's a viral infection, not a fungal one. She said because you are HIV positive, the only thing you must be given is Bactrim. I said that's only for people on stage 3. I went to the village clinic, we argued about the dosage but in the end they gave me what I needed! Nocawe Jijimba, TAC treatment literacy trainer, Oliver Tambo District, Eastern Cape (TAC, 2006, p. 19)

The TAC has brought together building people's knowledge of the science with the idea of the right to health as the motivating fire.

TAC members use Equal Treatment to build their own knowledge and then create opportunities to actively work with community members – through training workshops, through dialogues, through conversations at clinics.

The challenges that we experience are sometimes growing us to be better people – they challenge you and let you think through issues to the deeper

*core – it's not acceptable in the organisation
to sit with a challenge you don't act on – the
opportunities we get being illiterate as we are, but
you are fearless in approaching the MEC to ask
"what's going on about 1,2,3?" The educational
qualifications of someone else are not a threat
to us, because we know what is rightfully ours.*
Vovo Matiso-Gonyela, TAC provincial
organiser, Eastern Cape (TAC Eastern Cape
staff leadership, 2015)

Competing truths: whose science?

The TAC has chosen to give priority to some issues
over others and to some solutions over others, which
has been a source of tension within and outside of
the organisation as also discussed in the section on
gender power dynamics above.

Public health policy and interventions on HIV are
shaped by the dominant HIV/AIDS research, activist
and funding paradigms. Randomised clinical trials
(RCTs) on HIV prevention and treatment produce
deliberately decontextualised findings in order to
assess the probability of a specific intervention
working, without it being influenced by other factors
(Dowsett & Couch, 2007). For many, once there is a
finding from an RCT, it is considered the truth.

The vast bulk of research funding and of research
addressing HIV has gone into finding drugs to treat
HIV and into seeking technical (rather than social)
solutions to HIV prevention – the search for a
vaccine, the studies on medical male circumcision
(MMC), among others, relying on RCTs as the final
word on effectiveness.

However, it is well recognised that a study of a
clinical or technical intervention on the body
provides certain kinds of information, and a study
of the context in which that body and person lives
provides different information. In real life, multiple

factors influence an intervention, and sexual
health is profoundly influenced by social, cultural
and economic factors (Kippax, 2003). This has
led to substantial contestation in the HIV/AIDS
field regarding what types of evidence constitute
knowledge and why some forms of knowledge
are privileged over others (Rychetnik et al., 2004;
Walby, 2005). Arguments regarding validity have
to be navigated by MBOs, which means they have
to ensure that they draw on researchers across
different disciplines and paradigms and with a deep
understanding of the existence of "plural realities,
and how these are shaped by social, political, cultural,
economic, ethnic, and gender values" (Rychetnik et
al., 2004, p. 544).

Deep attention to the cultural and social constructs
around sexuality and reproduction is particularly
important in contexts where HIV is predominantly
sexually transmitted. Without explicitly exploring
these questions, "gender and rights issues tend to
evaporate" under the weight of dominant gender-
blind research approaches (UNDP/UNFPA/
WHO/World Bank Special Programme of
Research, Development and Research Training in
Human Reproduction, 2014, p. 3).

An example is the TAC's support for MMC. As the
head of PCR (policy, communication and research)
at the TAC, Marcus Low, noted in relation to the
findings of three RCTs on MMC:

> […] *we can't decide for someone to get
> circumcised or not; but we can say "the evidence
> is very strong that this will reduce this risk and
> you have a right to know this so you can decide".*
> (Low, 2015)

Once the MMC trials were complete, the TAC
chose to incorporate MMC as one aspect of
prevention – Eastern Cape reports include numbers
of men who have gone for MMC. The TAC then

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focused much of its attention on advocating against the use of the Tara Klamp[13], and was successful in stopping its use except in KwaZulu-Natal. This despite the high level of contestation during UNAIDS and WHO consultations regarding the ethics of initiating implementation in the absence of information about MMC effectiveness in uncontrolled and diverse contexts, and the lack of evidence on social and cultural dynamics that might flow from the intervention (Dowsett & Couch, 2007; UNAIDS/CAPRISA, 2007).

> "[...] efforts to promote male circumcision should move quickly beyond the narrow realm of biomedical intervention to engage with socio-cultural meanings and practices."
>
> *(Niang & Boiro, 2007, p. 31)*

The RCTs did not provide insights on how the intervention might influence sexual behaviour or women's sexual negotiating power, let alone insights as to how MMC might interact with local understandings of masculinity in those cultural contexts where male circumcision is associated

with rites regarding masculinity, among other things. To its credit, the TAC did include WHO recommendations in its own educational materials, emphasising that MMC provides only partial protection and must be used with a condom, and that it should not in any way undermine women's autonomous sexual decision-making (TAC, 2011). However, it did not insist that MMC should only be provided as part of an integrated package of sexual and reproductive health services, which the WHO advised in order to guard against potential unintended negative consequences of MMC.

This example simply illustrates the TAC's greater comfort with addressing questions of prevention technology rather than taking on the more fundamental questions of how social dynamics and sexual cultures interact with technical solutions – a terrain which is less tangible and has received far less research investment, and a terrain which requires more complex interventions than demands for specific treatment or technology to be available. That said, the TAC's strength may lie in part in its emphasis on treatment. Were it seriously addressing social determinants of health it would have to build a deeper skills base in shifting social and cultural values and behaviour, which is a more complex challenge than holding a constitutionally-bound state to account for service delivery.

[13] A clip-on-and-wear circumcision device which has been found to cause significantly more pain and adverse events than a forceps-guided surgical circumcision.

Movement-building

Political sophistication and adaptability

As the stories of the TAC's strategies and outcomes at national and provincial levels attest, the TAC has operated and continues to operate with a high degree of political sophistication. This includes working out how to position the TAC in relation to the political environment.

For example, in the early days of the TAC, Zackie Achmat's repeated assertion that he was a loyal member of the African National Congress (ANC) even while he was pushing the right to treatment for HIV was a master stroke in undercutting the ability of the ANC and the state to cast the TAC as anti-government. Also, the TAC's decision to illegally import Fluconazole at low cost showed up that the barriers to treatment were barriers that could be challenged with the requisite political will and commitment from corporations. Further, the TAC's decision to use 'civil disobedience' immediately harked back to the struggles of the anti-apartheid era and made a claim in the minds of the public and many politicians that those who experience injustice must speak out and get heard.

Similarly, in the current period, the TAC is navigating a trajectory of engagement and challenge, having to rapidly shift strategies as the context shifts from district to district, province to province, and nationally. Hence, while it can engage effectively in the KwaZulu-Natal Provincial AIDS Council, in the Eastern Cape it has at one moment gone and run a medicines depot, and at the next had to work in a major coalition to embarrass the government into action; similarly, in the Free State, it has had to challenge government for its failure to hold the political leadership to account – in the Fire Benny campaign – and support community health workers in a court case against their dismissal by government when they play a role required by that same government's health policies (Cullinan & Nkosi, 2015).

> The TAC is navigating a trajectory of engagement and challenge, having to rapidly shift strategies as the context shifts from district to district, province to province, and nationally.

In different ways, the TAC continues to manoeuvre to powerful political effect – for example, that government leaders feel obliged to respond to criticism. That said, the TAC has to put in a sustained effort to monitor that the content of policy stays supportive of the interests of the majority as it is developed.

The TAC is having to carefully position itself in a political context in which there is tremendous contention between the TAC's erstwhile allies, in particular with ruptures in the Congress of South African Trade Unions (COSATU[14]). Groups that are in contention with each other are all wanting the TAC and its membership to get involved in their campaigns and alliances. Yet the TAC is still managing to sustain alliances that further its own goals.

Mobilisation versus organisation

It is one thing to mobilise people to come to an event; it is a much deeper enterprise to organise a movement – building ongoing relationships and skills so that people become the assets of an organisation, activists and leaders. Organising a movement also means decentralising so that branches can act autonomously to achieve the overarching shared goals of the MBO (Han, 2014).

This deeper work is central to the TAC – it has a branch structure, with each branch electing leaders who help coordinate actions at local level. The TAC's existence at local level provides a point of reference for local community members who come

to the TAC with problems not only around HIV and treatment but also around multiple local issues. This gives branch members the basis for organising and for action (Taylor et al., 2015), which in turn forms the foundation of the TAC's authenticity – that it represents the lived experiences of ordinary people. NGOs and academics may research an issue, but nothing can replace the credibility of organisations that can give voice to issues emerging from the daily lived realities of individuals across a country.

Communication without cost

Social media for mobilising and for organising

The challenge of local-level organising is keeping the whole together. More so when many members are both unemployed and impoverished and do not have funds to cover phone calls or local transport, let alone have access to the internet. The TAC is highly innovative in this regard, including increasingly using social media.

> The challenge of local-level organising is keeping the whole together. The TAC is highly innovative in this regard, including increasingly using social media.

[14] COSATU has until recently been the primary federation of progressive trade unions, but it is now riven with tensions over both political positioning, and political and economic vision for the future.

Members use WhatsApp to organise[15] – in most provinces, TAC chairpersons have a WhatsApp group and branches are starting to do this too. They use it for the "nitty-gritty of organising" (Low, 2015) – for example, setting and reminding people of meetings. Similarly, the TAC will set up a WhatsApp group to coordinate members' participation in major events such as the national AIDS conference.

Members also often use Facebook to organise – "I see branches developing on Facebook" (Blose, 2015). This process also strengthens people's sense of being part of a political structure and organisation. TAC Director of PCR Marcus Low warns, however, that:

> [p]eople think you don't have to organise because of social media, but the bread and butter is still Saturday morning taxi ride to the meeting and sitting there for hours engaging the people. (Low, 2015)

Social media for gathering evidence for advocacy

TAC members also use WhatsApp during campaigns to share information, which strengthens their strategising and advocacy. For example, if people see an article relevant to the work, they take a photo and send it to the group so that everyone working on the issue is aware of it.

The TAC's PCR department also has a WhatsApp group – "Today with the silicosis case happening in court I kept getting updates from my department's WhatsApp group" (Low, 2015).

Members are also using WhatsApp to capture and communicate the situation on the ground. For

example, they developed a checklist of 'yes' and 'no' answers that members used to assess infection control at health care facilities. Depending on the number of 'yesses' and 'noes' they then rated the facility red, orange or green[16]. They used WhatsApp to send the name of the facility, the colour rating, a picture of the facility and a short comment to the TAC's PCR department – covering 60 clinics in all, most of which were red or orange. The PCR department then collated this information and used it as part of its World TB Day statement, and the memorandum it gave parliament – "We're aware that it's not rigorous scientific data, but it flagged something that needed to be looked at" (Low, 2015).

The SSP (Stop Stockouts Project) similarly gives TAC members and community members a card with a phone number to which they can WhatsApp information about medicine stock-outs.

The TAC's PCR department recognises that each medium has different audiences and roles. Facebook is the general public, which is important for branding – for example, General Secretary Anele Yawa's page builds him as part of the TAC brand and he keeps followers up to date on the TAC's political concerns, activities and approach. In contrast, Twitter is used more by journalists and analysts, and the PCR department often picks up photos and commentary sent in by members with WhatsApp, provides a caption explaining the issue and sends it out on Twitter where others re-tweet it, which helps the TAC maximise the reach of its information and its local actions. At times, the TAC commissions professionals to make videos when it needs high-level production values in order to attract attention of specific audiences.

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[15] South Africa has universal coverage of cellphones. It has a system where people can send free 'call me' text messages. Some service providers offer use of WhatsApp at no charge.

[16] Red being 'most controls not in place'; orange being 'some controls not in place; and green being 'working as required'.

Building a base takes time and long-term core funding

While WhatsApp facilitates local organising, it does not solve the challenges of the costs of on-the-ground organising or of building coherence across a decentralised organisation with branches and provinces taking multiple actions at any one time.

The public story of the TAC focuses on what the TAC achieves – its outcomes. However, achieving such outcomes requires a functioning organisation not only with formal systems (for knowledge management, financial management, good governance, compliance with labour laws, and so on) but also an organisation that is in a constant state of connection and internal reflection – sharing experiences about what has worked and what has not; and working out what kinds of strategies are most likely to be effective in what contexts (Heifetz & Laurie, 1997; Reisman et al., 2007).

> The public story of the TAC focuses on what the TAC achieves — its outcomes. However, achieving such outcomes requires a functioning organisation not only with formal systems but also an organisation that is in a constant state of connection and internal reflection.

To do this in a national MBO means creating institutional spaces for information sharing and reflection. When the TAC has resources, it has quarterly meetings of its national council – comprising the executive team, provincial coordinators (staff) and provincial chairpersons (elected) as well as some partners (MSF, the RHAP (Rural Health Advocacy Project), S27 and Sonke Gender Justice). Its board of directors also meets quarterly.

When it has resources, the TAC similarly has quarterly meetings of office-bearers in each province (provincial councils) – these are meetings of all branch chairs to close the loop of information and reflection across the organisation. When the TAC does not have funds, it uses teleconferences, which are a poor substitute given poor line quality, and it becomes much harder to remain a learning organisation with strategies that are finely tuned to the shifting political, economic and cultural terrain.

Project funding cannot sustain organising or learning

The power of a membership-based activist organisation is its ongoing engagement with its members in an intensive cycle of planning, action, reflection and learning.
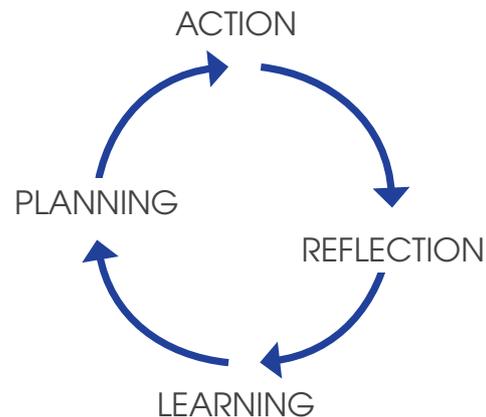

Figure 6: Reflection and learning as key dimensions of the organisational process

When there are only funds for action and not for reflection, such an organisation can fail to sustain the motivation or skills of its members and lose its strategic edge. This is the fundamental flaw of donor

approaches that only support projects rather than provide flexible, general or core support.

The other limitation of project funding is that it assumes predictability. Yet at the heart of the MBO model is responsiveness to individual needs and to political issues that arise unexpectedly. The TAC's willingness and ability to listen and respond to member experiences is at the core of its effectiveness, yet project funding is often framed around deliverables determined in advance, sometimes in offices far removed from the TAC, sometimes at the TAC head office away from community-driven dynamics.

The TAC's Prevention and Treatment Literacy Programme is at the centre of its method of recruitment and of efforts to sustain both membership and individual members' ability to feel recognised and make use of and demand quality services. It is these members who bring reports to TAC leadership when services are not available or go wrong. This happens in real time and real situations; individuals and groups come to trusted organisations that are on the ground. The TAC has branches in tiny villages where there are no NGOs or government services to be found. A key value of MBOs is this kind of reach and willingness to take action that simply could not have been planned in advance.

Many people work in the same field as we do but not all of us are activists. Here is a story that shows the difference. There is an organisation we know well. They provide mother and child health services. They do great work. The other day the TAC office gets a call from one of their community health workers. They have come across a family of three children who have not been immunised. Their mother is dependent on and abusing drugs and being abused by her partner. There is clearly no way she is going to get the children to the clinic. The provincial coordinator takes the call. He does not ask the health worker why they have not acted. He senses they are not activists and that is why they had made the call. He takes the address and gets up from the pile of reports he has to complete. He goes out to his old car, and at his own expense, drives into the township. He finds the children and locates their grandmother. He bundles them into the car and drives to the clinic. The sister tells him it will not be possible as the children do not have the correct registration papers. He knows that it will and tells her so. He knows the law and the children's rights. He knows the policies and procedures of the health services. He knows who the clinic sister's manager is and her phone number. He asks the sister to phone the number and to pass the phone to him. He leaves with the children immunised. He drops them and their grandmother back at home and returns to his reports. (Taylor et al., 2015, p. 29)

One might ask: why is the TAC working on immunisation? The answer is clear: this local responsiveness builds community trust; it also recognises that people are not just people infected or affected by HIV but that other issues are as important for their survival. This is part of the reason why the TAC's remit is shifting towards the right to health generally rather than only the right to treatment. The level of commitment and knowledge of the law, confidence in the right and capacity to advocate, as well as relationships with health service providers make the TAC the go-to group not only for community members but also for NGOs who are limited in their own mandates.

Project funding, however, does not support local responsiveness – whether to individual needs or by mobilising whole communities on unexpected issues or unpredictable crises – which is key to building trust and the reputation of an MBO.

> TAC needs much more discretionary funds – which does not mean no accountability since there will be audits and annual reports. It is absolutely essential that the political leadership should be able to assess that the work in – say Gauteng – now requires focus and be able to shift funds there as needed. At the moment this doesn't happen. Funds are stuck in the wrong budget lines. Over the last five or so years, TAC has been put in a donor straightjacket that has threatened its ability to respond to a wider variety of issues and to be more responsive in relation to its core work. (Low, 2015)

> "TAC today is complex [...] You need to submit plans, you need to submit budgets, you need approval ... [*Before*] we could react so quickly."
>
> *Mandla Majola, provincial coordinator TAC Western Cape (Stephen, 2009, p. 164)*

Change comes through partnerships and alliances

TAC staff and members are careful not to make claims only for the TAC. When describing their achievements, they consistently name those they work with. Among these, some key groups have formal ongoing partnerships. While the TAC brings to the table the experiences of those on the social margins who are living with a stigmatising disease and attempting to access quality services, the organisation needs partnerships with groups that bring other skills.

> "TAC succeeded in leveraging 'networks of influence' (which also included scientists, bureaucrats and politicians) to contribute to the formation of a moral consensus on treatment access and the construction of an inclusive coalition that pursued policy change."
>
> *(Grebe, 2011, p. 849)*

S27 is a key TAC partner and brings an ability to identify legal avenues of redress for issues that members are experiencing – using the law to challenge the legality of quacks selling untested 'medicines', for example, or to challenge corporate patents that were preventing affordable treatment.

There are detailed histories and analyses of the specific work of the TAC with S27 (or as it began, the AIDS Law Project) (Geffen, 2010; Heywood, 2009; Moyle, 2015) as well as a fine analysis of the relationship between social mobilisation and litigation (Budlender et al., 2014) – which is why this report does not focus on the TAC's litigation strategies. S27 describes the relationship between itself and the TAC as follows:

> *Section27 and the* [TAC] *are two independent organisations.* […] *Our respective roles, joint projects and points of intersection are clearly set out in a Memorandum of Understanding approved by our board of directors. Activists and leaders from the TAC are in constant contact with activists at Section27, bringing us to the front line of clinics, decaying hospitals and medicine shortages. TAC shares community insight, wisdom and leadership. Section27 shares and utilises its knowledge of human rights law, the Constitution, the law and policy-making process in health and in the courts.* (Section27, 2013, p. 85)

MSF in South Africa is another important TAC partner. It brought clinical experience of high-quality service delivery to those who, in the early days it was claimed, could not adhere to treatment because of their illiteracy. A partnership between MSF and the TAC proved such nay-sayers wrong. The current partnership between the two organisations takes multiple forms. For example, MSF's parliamentary monitor is based at the TAC's offices in Cape Town and keeps both organisations tuned in on the policy side; also, as seen further above in box 2, TAC members worked alongside MSF in making the Mthatha Medicines Depot functional when it collapsed.

Likewise, the TAC has a multiplicity of relationships with researchers and research groups, which allow it to keep abreast of current scientific information. Internationally, MSF's Access Campaign is one of the TAC's key sources of information and analysis for its Fix the Patent Laws campaign. Two other organisations – Knowledge Ecology International and Public Citizen – also provide input to the TAC on patent-related issues and are advocacy partnerships; for example, Public Citizen wrote a submission specifically on South Africa to the US Congress regarding efforts by pharmaceutical companies to influence it to make its support of African economic growth conditional upon South Africa not passing the Intellectual Property Bill.

> "This movement illustrates the power of transnational mobilisation to help bring about 'moral consensus' and to deploy influence and social power at the global level sufficient to overcome substantial corporate power."
>
> *(Grebe & Low, 2014, p. 1)*

The Southern African HIV Clinicians Society is generally seen as an amazing source of good information, endlessly willing and able to make new technical information accessible by running workshops for TAC members – frequently taking advantage of spaces such as the national AIDS conferences when people are together.

HIV i-Base in the UK provides substantial technical assistance to the TAC, for example, in the writing of the TAC's publication *HIV in our lives* or for training TAC members in treatment literacy.

Similarly, the Treatment Action Group in the US provides quick information on who is taking up what issues internationally, as well as writing articles for the NSP Review, among other things. The TAC also uses their reports – for example, about new medicines – to keep itself and its members informed.

The Community Media Trust brought the capacity to film the TAC at work, creating videos that took the TAC's message out nationally and internationally.

Health-e News brought the TAC trained journalists, and more recently citizen journalists (community activists trained by Health-e News to capture and write local stories – some of them TAC members) who could tell the TAC's story and get it into state and independent media.[17]

Relationships built over the years, coupled with the TAC's strong brand, allow it to call upon those with expertise – for example, at the time of writing this report, it had held a TB experts meeting to ask top academics in South Africa what the TAC could do to influence national attention to TB.

The TAC has also built significant partnerships with individuals and organisations (such as Friends of the Treatment Action Campaign, a UK-based charity) that have supported it in fundraising, including with individual singers, notably Annie Lennox and currently Johnny Clegg in relation to TB.

Contemporary understanding of social change recognises that the terrain is a complex system

[17] See the report *Social justice journalism – lessons from Health-e News,* which is part of the same Atlantic Philanthropies-supported strategic learning initiative that has produced this report on the TAC.

with multiple players with multiple interests, all pushing their own agendas in rapidly changing environments (Patton, 2012; Williams & Hummelbrunner, 2011).

> "[...] policy work [...] requires multiple players "hitting" numerous leverage points."
> *(Guthrie et al., 2005, p. 9)*

To be effective, groups need to make alliances with as wide and diverse a range of groups and capacities as possible, all the time working to sustain a shared understanding of the issues and a shared demand, to agree on the framing of that demand, and to each do what it does best in order to make progress (Klugman, 2011; Plastrik & Taylor, 2006). For this reason, organisations need to challenge any pressures put on them – by their boards, their donors, or by the media – to claim that they alone have made change happen. In most cases, multiple organisations contribute towards change and should be rewarded for collaborative rather than competitive relationships.

Single-issue focus versus demands for an accountable and respectful state

The TAC's strength is its single-issue focus, with its initial strategies aiming to realise the right to treatment, and once that was won in principle, its strategies aiming to realise the right to health and health care. It has built a membership base that allows it to identify and address barriers to realising these rights, but it was established and continues to operate within a broader political consciousness – the post-apartheid dream of dignity and rights for all. In this context, the TAC has felt duty-bound to act in solidarity with the suffering of others. For instance, it was this that led the TAC to mobilise its own members against the xenophobic attacks

that came to a head in 2008, and again in 2015.[18] Speaking out and organising marches in partnership with others is done on the principle of political solidarity, locating the right to health as part of a bigger political agenda of freedom and dignity for all, and the demand that the state delivers on its constitutional commitments.

To the outside eye, the TAC's strength is frequently described as its membership; partnering with the TAC means gaining access to a base of support. The challenge for the TAC is how to assess when solidarity requires it to lend its voice and its numbers to an issue, and when this distracts the TAC from its primary purposes. This is made more complex by the fact that enabling a visible show of support costs money, given that TAC members are largely unemployed and cannot cover costs of getting to distant venues, meals while on the road, and so on. But what if donors offer large sums of money for this 'other' issue? In this vein, despite its need for funds, the TAC recently said no to an offer of substantial funds for mobilising against xenophobia, because of its leaders' concern with mission drift.

This conundrum is faced by many MBOs because their own issues are frequently a reflection of broader social problems, and the more one can build alliances across multiple issues, the more one can build public consensus for a deeper social change agenda (Laclau, 2005). In this case, the right to health is embedded within two broader claims:

• the right for all people in South Africa to be treated with dignity and respect, and to be recognised by arms of state (as well as the private sector and civil society) – that is, within civil and political rights

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[18] This decision in particular begs the question as to why the TAC has not given higher national profile to its work to challenge gender-based violence, given its prevalence.

- the right for all people to realise the socio-economic rights to which the South African Constitution commits the state.

At times, the TAC finds a confluence of interests – for example, it is deeply concerned about the situation of people stigmatised because of their sexual orientation or gender expression; the stigma itself is unacceptable and it increases the vulnerability of LGBTIs to HIV transmission and their reluctance to seek services for fear of hostility. In this context, the TAC created a partnership with an international NGO to work on these issues. TAC staff note, however, that if the NGO ends its funding, it is the TAC that will have to continue to meet the expectations of members and of the public to organise and speak out on the issues.

Partnerships require time, funds and organisational processing

A major challenge for the TAC is that many health and other NGOs are looking for an organisation with a mass base to take forward their issues, and so they seek partnerships with the TAC. Sometimes groups which take money from government fear speaking out and look to the TAC to speak on their behalf – "[*W*]e can say what we want, when we want, where we want, and know no funding will be taken away from us." (Booysen, 2015)

The RHAP notes that the TAC is the only membership-based group in South Africa with elected leadership that reflect the experiences and demands of those in rural and impoverished areas. While the TAC sits on the RHAP's board and participates in its campaigns, the RHAP is one of many groups wanting the TAC to play this reflective and representative role. The absence of grass-roots movements on other aspects of health – mental health, disability, sexual rights, gender-

based violence – means everyone looks to the TAC (Versteeg, 2015).

Irrespective of the TAC's commitment to an issue or the degree of synergy with its own issues, every commitment to participate in a coalition or to work with another organisation requires the TAC to allocate time and resources not only for partner meetings but also for taking the issues through the organisation to members and to leadership. In a decentralised organisation this is a major commitment, particularly when those representing the TAC in such partnerships may be volunteers.

Monitory democracy

The role of MBOs in constitutional democracies is frequently to make sure that those on the margins – whether because of their poverty, their distance from cities, their sexuality or their citizenship – are represented. Understanding this role means recognising that a democracy requires ongoing external critique if those who hold power and resources are to remain faithful to constitutional intentions. Having powerful external voices is key to democracy and should not be a source of anxiety for MBO funders or potential partners, who sometimes frame this as 'too political'. How to best play this monitoring role depends on the issue, the political context and the way those with power exercise that power.

"'Monitory democracy' is a new historical form of democracy [...] a complex web of differently sized and more or less interdependent monitoring bodies that have the effect, thanks to communicative abundance, of continuously

> stirring up questions about who gets what, when and how, as well as holding publicly responsible those who exercise power, wherever they are situated."
>
> *(Keane, 2011, p. 231)*

At the heart of a monitory democracy is the capturing of evidence of the extent to which government is delivering on its constitutional mandate. The TAC plays this role by taking up issues faced by individuals in communities, where the TAC will give them support or take issues up with local health facilities, but also by gathering data that the TAC's national office then collates to use for advocacy. Key to the TAC's effectiveness is its ability to get its data and analysis of that data out to a very wide audience.

Combining insider and outsider strategies

In most cases, the TAC uses a mix of strategies that aim to build public concern for the issue, including media concern, so that the public is informed and able to express itself to and engage with those in power. Where it can access decision-makers directly, it does so; where it can engage in existing policy forums, it does so; and at times, it creates decision-making platforms.

When reaching out to those with power yields no result, the TAC will mobilise those affected to make their concerns public. This can be described as a mix of 'insider' and 'outsider' strategies (Jones, 2011; see also box 4 overleaf) – building public pressure on the outside, often serving as a push to those with power to be seen to be engaging an issue.

The idea of 'invented' versus 'invited' spaces also helps to understand the TAC's positioning. Given that there are multiple official forums – that is, 'invited' spaces – for civil society participation, the TAC tries to maximise effective participation of its members and other community members in these. But the forums frequently have "technicist and state-centric approaches to democratic participation" (GGLN, 2011, p. 7) and are subject to political capture by specific political parties (Paulus, 2015) or lacking in adequate capacities – hence the need for the TAC and other civil society groups to also invent spaces for engagement.

Box 4:

Insider and outsider strategies to achieve health service responsiveness

In November 2014, the Nelson Mandela Metro Municipality closed the Mabandla Clinic in Uitenhage, Eastern Cape, because nurses had been hurt during a service delivery protest against a corrupt city councillor whose office was adjacent to the clinic. The clinic reopened the next day but then closed again.

The TAC spoke to the district health manager and clinic supervisor, but they did not take action. On 28 January 2015, the TAC wrote to both of them asking that the ward councillor be made to move his offices, that the clinic be reopened, and that the health care providers be given counselling to cope with the harassment they had experienced. The TAC asked for a response within 10 days. In the absence of a response, the TAC and allies held a sit-in at the office of the district health manager in Port Elizabeth to demand a response to the letter. The TAC then mobilised community members to engage those involved in the service delivery protests that were affecting the Mabandla Clinic, encouraging community leadership to protect their own (clinic) infrastructure.

The TAC encouraged community groups to participate in the District Health Forum – a platform that represents all clinic committees – and there built their knowledge of the Bill of Rights, the Patients' Rights Charter, the district health system, and the importance of prevention and treatment, including adhering to treatment for HIV and TB. The TAC also reached out to potential allies.

Outcome:
In February 2015, the ward councillor met with the TAC. However, he did not agree to move

his office. Also, the district health manager responded to the TAC by denying that the clinic was closed.

On 4 February 2015, the TAC wrote to other ward councillors responsible for health in the metro and to the provincial MEC for health, demanding her intervention. Even the metro HIV/AIDS coordinator was not aware of the clinic closure.

On 11 February, the TAC wrote to the Eastern Cape secretary general for health and engaged the head of the Eastern Cape Provincial AIDS Council, none of whom were aware of the closure of the clinic despite it serving 6,000 patients a month. It was unclear who gave the district health manager the power to close the clinic.

Outcome:
- on 12 February 2015, the TAC secured a meeting with the human resources manager of the Nelson Mandela Metro and the provincial district support manager, and invited health worker organisations – the Democratic Nursing Organisation of South Africa (DENOSA) and the Health & Other Services Personnel Trade Union of South Africa (HOSPERSA) – as allies, as well as Mabandla Clinic staff and the clinic committees mentor. There, they collectively came to an agreement on short- and long-term plans

- the TAC also secured attention by the media and was interviewed by the Herald and the Daily Sun newspapers immediately after the meeting

Box 4 (continued)

- in this process, the district health manager was recalled from her duties and a new one was appointed
- the clinic was reopened on 13 February 2015 with commitments to fence it, provide security guards and establish a procedurally correctly elected clinic committee.

Despite the commitments made, it was the TAC that had to organise and convene a meeting bringing together local and district management as well as the Infrastructure Unit of the national DoH, the clinic supervisor, the District Health Forum and local political parties on 5 March to ensure that the process moved forward.

Outcome:
The stakeholder group planned a community meeting, briefed national DoH Deputy Director-General Yogan Pillay on what had happened and their expectations moving forward, and met with the new district health manager for input on management's plans to implement the agreements.

The TAC then convened the community meeting on 13 May 2015.

Outcome:
The process of establishing a community clinic committee was discussed at the meeting. Nomination forms were distributed and due date for submissions agreed upon in order to allow screening and approval of nominees by each nominee's own organisation.

In addition, the TAC distributed nomination forms to organisations who had an interest in serving on the clinic committee for Mabandla Clinic since it did not have a properly constituted structure. Theodorus Nogampula – who is both a TAC member, and an (elected) member and secretary of the Sub-district Health Forum – facilitated the election process.

Outcome:
Clinic committee community members were selected on 18 May 2015.

(Matiso-Gonyela & Nogampula, 2015)

Monitory democracy means adversarial relationships are key to making the South African Constitution work. Where the TAC can use its relationships and its position inside policy forums to make progress, it does so; but when it needs to mobilise members and the broader affected community as well as other interested stakeholders, it does so. Significantly, in the 2015 CDRA (Community Development Resource Association) evaluation of the TAC, a number of health care providers spoke about how even when the TAC appears adversarial, it is making a significant contribution towards strengthening health services.

I was taken to interview the CEO of a district hospital [in the Western Cape] by a provincial coordinator. On the way I was told of the protests that had taken place to demand quality services from the hospital. I heard of the heated encounters that had taken place between the coordinator and the CEO on these occasions. On arrival this history was confirmed in the greetings between the two. The CEO insisted that the coordinator stay to hear what he wanted to say in the interview. His message was that the purpose and the quality of the work of the hospital could not be achieved without TAC – without the people constantly demanding quality care and being prepared to work tirelessly for it in the

communities they represented. He explained how the protests that made his life difficult helped him bring about change and acquire much needed resources in his system that he could not achieve on his own. The CEO explained that his appreciation for TAC was not shared by all his colleagues in the system. He explained how you have to be able to stand back to see the big picture – how maturity was needed to appreciate the fact that those who at times make life very difficult for you actually share the big picture of striving for a quality health care system. CDRA evaluator (Taylor et al., 2015, p. 30)

Engaging decision-making spaces

One of the signs of the shift to monitory democracy is the burgeoning of multi-stakeholder forums where government, the private sector, and civil society bring their collective wisdom to resolving issues. With the end of denialism, the TAC and its partners, particularly the AIDS Law Project – now S27 – and MSF, put a tremendous amount of time and negotiating effort into the establishment and running of SANAC (South African National AIDS Council). The Council's mandate is to:

> […] *build consensus across government, civil society and all other stakeholders to drive an enhanced country response to the scourges of HIV, TB and STIs.* (SANAC, 2013)

SANAC has multi-stakeholder structures in every province and every district of the country, all of which are tasked with the implementation of the NSPs – currently the NSP for 2012-2016.

As noted earlier, the TAC and S27 jointly publish the NSP Review that monitors implementation of the strategic plan, drawing attention to specific challenges such as drug-resistant TB, the failures of the National Health Laboratory Service, or the

vulnerability of teenagers to HIV. The TAC and S27 print and distribute 7,000 copies of each edition.

AIDS Councils

Yet over time, the TAC has often experienced itself as a lone voice in the national, provincial, district and local AIDS Councils. TAC staff argue that most other civil society groups that participate have funding from government and fear losing it, so they do not speak out to challenge government even when they see the need. Indeed, sometimes they provide the TAC with evidence of problems and ask the TAC to speak out for fear of doing so themselves (Serote, 2015).

> The TAC has often experienced itself as a lone voice in the national, provincial, district and local AIDS Councils.

Hence AIDS Council meetings at all levels become spaces for top-down imparting of information rather than for listening to individual and community problems, identifying blockages and resolving them. Government frequently asks the TAC why it does not rather raise its issues through SANAC, but the TAC has repeatedly found that:

> […] *the issues we take to SANAC die at SANAC. There is certainly a sense that AIDS Councils often function as mechanisms for co-option rather than for meaningful participation.* (Low, 2015)

The TAC has had some positive experiences with AIDS Councils – for example, the KwaZulu-Natal Provincial AIDS Council is currently a vibrant space for problem solving; but the general problem was raised repeatedly in the Eastern Cape.

It was not easy to work with the Provincial AIDS Council – we had demanded a special meeting to talk about these quack medications and they didn't know how to intervene and why this was their baby; they didn't know how to hold this pastor accountable – they said only the premier or MEC could call him to order as community members chose to go to him to use his services. We gave them a summary report. Noloyiso and Fiks[19] are on the AIDS Council but it's not as easy to work with, because they see TAC as an advocacy group, and when we identify issues they respond as if we're looking for trouble; we're labelled as a group that is arrogant and aggressive which pushes people to do as we want; they don't want to acknowledge that we're bringing in evidence or problems and ways of addressing those problems; they find it hard when TAC brings suggestions and leadership, but if we see an action is needed we move ahead. We have to remind them TAC is an independent organisation representing people living with HIV. (TAC Eastern Cape staff leadership, 2015)

AIDS Councils seem more like a government affair – resources go to people who know people rather than them being deeply knowledgeable. They haven't worked as a civil society/government

forum. We ask local municipalities for the AIDS Council budget and plan but it's not there. For example, in the Provincial AIDS Council there's someone supposed to be coordinating social mobilisation but where's the budget? There is no budget. If there were a budget, when we do our mobilisation they would provide money. They're just calendar-driven – you'll see money for their own tenders for World AIDS Day, for Condom Week – someone providing a tent and catering comes all the way from East London to Lusikisiki. Last year – 2014 – we said no to this. In fact, at SANAC the message was clear on this but they never cascaded it down; when we tried at local level they said TAC was causing confusion. Still, we were successful because we said "it's not just about 1st of December, there must be a change in programme – Provincial AIDS Council can no more hire a musician to come sing for R90,000 [almost US$7,000] for World AIDS Day. We got the premier and MECs to do door-to-door work, to visit facilities, checking the suggestion boxes – so we changed the meaning of the World AIDS Day activity. For example, we got them to visit an old age home in Buffalo City that had no cleaning material so the Department of Health was told to deliver equipment there. So it's not just celebrating and mourning people who had died but an impact on those alive. (TAC Eastern Cape, 2015)

19 TAC Eastern Cape Provincial Coordinator Noloyiso Ntamenthlo and Chairperson Fikile Boyce, respectively.

We seem to spend more and more time and energy in meetings around tables. In these meetings we become a part of decisions that are then not implemented in ways that help our members. When we take up the issue we are told that we were part of the decision so must take responsibility for it. I often wonder if we should not rather go back to being activists. Active branch member (Taylor et al., 2015, p. 32)

Clinic committees

As with the AIDS Councils, the TAC similarly works hard to support the establishment of legally required clinic and hospital committees[20] (see box 4 further up) and often has members on such committees.

However, for clinic committees to work effectively, there has to be a shared understanding between clinic staff, community representatives and political leadership as to their roles in promoting primary health care. Without this, community representatives on clinic committees lack agency.

Clinic committees have not been established in many facilities, and where they do exist, they are not resourced and seldom fulfil their intended functions (Mdaka et al., 2014). Neither financial resources, nor process guidelines are provided by government to facilitate effective participation of community members (Padarath & Friedman, 2008).

In this context, the TAC often takes the role of building the understanding of community representatives regarding their roles, about the responsibilities of clinics and about patients' rights.

[20] Section 42 of the National Health Act, No. 61 of 2003 stipulates that the following people must be members of clinic committees: one or more local government councillors; one or more members of the community served by the health centre; and the head of the health centre in question.

The TAC builds the confidence of community representatives to make claims in the face of clinic and DoH authorities.

Hence statutory mechanisms of monitoring democracy do not automatically work unless there are people in government or civil society investing in making them effective. This is a key role that the TAC plays. But in a context of discomfort by clinic staff and political leadership, it is not easy for TAC members to be lone voices.

> "Realising the right to participation means creating conditions under which people shift from being objects upon which government and others with power act, or fail to act, to becoming change agents within political processes."
>
> *(Klugman, 2010, p. 3)*

Efforts to promote participation have to focus on empowerment, which includes providing information and creating opportunities for self-reflection and analysis as the basis for effective decision-making and confident engagement with individuals and structures of power (Roa & Klugman, 2015).

Because of the difficulties of working effectively within statutory civil society-government forums, it remains important that MBOs retain their independent voice and their right to protest even while also participating in such forums. It is also important to ensure that statutory mechanisms for participation properly fund community members' participation – both transport and childcare costs as well as costs of keeping all members up to date on human rights, relevant laws and policies.

Outcomes 2010-2014	Women	Men	Unspecified	Totals
HCT (HIV counselling and testing)	194,868	80,250	79,000	354,118
TB screening	65,829	26,643		92,472
	Female	Male		
Condom distribution	341,416	50,900,000		51,241,416

Table 5: HCT, TB screening & condoms – numbers of beneficiaries reached by the TAC on a national scale 2010-2014

Monetary tensions

The impact of funding membership-based organisations for service provision

As donors sought to support the implementation of the NSP, funds became available for civil society, and the TAC took advantage of this to provide subsidies to more of its volunteers to undertake prevention and treatment literacy work and to monitor health service delivery. SANAC managed the proposals to and disbursement of funds from the Global Fund to Fight AIDS, Tuberculosis and Malaria. As national orientation, including that of the TAC, shifted from the struggle for the principle of the right to treatment to the struggle for actual service delivery, the TAC's strategies and commitments were increasingly framed by the NSP.

In 2010, the TAC agreed to shift its attention from its branch structure to focusing on the establishment of six model districts, which would serve to provide lessons on implementation for the nation. Many of the TAC's donors valued this shift as it allowed a more 'traditional' funding model supporting work to achieve relatively predictable outcomes that could be measured – numbers of people going for treatment, numbers of condoms

distributed, and so on, as reflected in table 5 adapted from the CDRA evaluation (Taylor et al., 2015, p. 25).

Membership-based organisations as service providers

The TAC took on the role of contributing towards the NSP with great commitment. This has had positive consequences for health services and PLWHA, and has built the TAC's relationships with people in the health system as well as its visibility in the model districts where it focused on NSP implementation.

AIDS-specific laws and policies as well as laws and policies aimed at promoting SRHR (sexual and reproductive health and rights) emphasise the need for outreach, awareness-raising and public participation. Yet these are mostly unfunded or poorly funded mandates. In the case of HIV, government predominantly left this to the Global Fund to finance – an under-resourced outsourcing of public sector responsibilities.

"[...] the voluntary sector can act as an alternative form of public service contractor [*which*] can create two areas of difficulty: First, undermining the genuine delivery of public services [...] relying on the element of voluntarism as providing a below cost solution to immediate financial difficulties. [...] Second, [...] acting to "professionalise" what should be a level of voluntary activity."

(Public Administration Select Committee, 2008, p. 205)

An external evaluation of the TAC's Treatment Literacy Programme in KwaZulu-Natal, Limpopo and the Eastern Cape at the height of the TAC's focus on service delivery in the model districts noted that, in this new role, the TAC had critical service provision functions.

DoH officials observe that in the process of undertaking all this work, the TAC has provided a model for government. They state that health care workers were supposed to do health talks but they were not doing it because of their workload and this makes the work undertaken by the

PTLPs [prevention, treatment and literacy practitioners] *really important. They also emphasise that* [the role] *the PTLPs undertake in facilitating the SG's* [support groups] *is also critical and they state that the clinics have really begun to see the value thereof and the way in which through this work, they are able to enhance the linkages between the clinics and the community.*

Of concern though is that interviews point to the high levels of dependence on the TAC. One sister states that there is a lack of capability at the clinic and she indicates that this "deficiency" is only addressed by the work of TAC. Interviewees from all levels of government, including the clinic staff, confirmed this perspective. They state that if the TAC pulls out of the clinics the impact will be extremely devastating for both the staff and patients. (Singizi cc, 2011, p. 19)

The same evaluation notes that TAC branches played key roles in going door to door in communities, encouraging and getting people to use the clinics and get treatment; in assisting clinics to track people who defaulted in their treatment; and in helping to establish and sustain support groups and clinic committees. Of major significance, evaluators also got feedback from health officials and clinic staff that "they rely on branch members to provide them with up-to-date information." (Singizi cc, 2011, p. 19)

TAC members note that, over time, health care providers began to treat the TAC as if they were employed by the DoH.

> *There's a confusion of roles. The other day a nurse in the metro asked TAC members, 'how many times do you distribute condoms? and we said 'twice a month or once a month.' She was furious, asking us 'why not every day?' We thought she was in the wrong place forcing us to do her duties. If she wants that she must employ people.* C-J Theodorus Nogampula, branch member Port Elizabeth (TAC Eastern Cape, 2015)

Despite the TAC's commitment to implementing the actions for which it was funded by the Global Fund under the NSP, the way in which it had locked itself into predictable activities specified in logical frameworks, typical of both national policy implementation plans and of multilateral donor requirements, started to undermine the TAC's essential role as a community mobiliser and advocate.

> "Very quickly the legitimacy of a federation or umbrella group can be undermined as the staff and board look more towards external funders than to their membership for guidance on their strategies."
>
> *(Pratt, 2009, p. 4)*

Also, despite policy commitments, when Global Fund systems failed or when it stopped funding, so did the work. In the process, the TAC had reorganised itself in ways that filled government's service delivery gap but undercut the TAC's depth and breadth of organising.

> "Before we were a campaign organisation – the characteristic of a social movement – and then we had to change our vision and objectives to focus on model districts."
>
> *Sindi Blose, TAC national deputy general secretary (Blose, 2015)*

In March 2013, the TAC abandoned the model district approach because it had fundamentally weakened the organisation's unique contribution to the field – those branches that were not in model districts had not received support from TAC staff, who were now mostly funded to work in districts. In addition, the strategy to focus on working and meeting targets in clinics had meant less attention to training and building capacity in branches (Singizi cc, 2011). The TAC's membership base had dropped to a low of 2,700 across 90 branches.

Also, the TAC had faced two internal crises in large part because of the way it grew during this time. In 2008, when funding from the Global Fund was delayed because of Global Fund-SANAC dynamics, the TAC had to retrench 10 members of staff and terminate stipendiary contracts of all 315 PTLPs, trainers, peer educators and material distributors. In 2012, when funding from the Global Fund ended, the TAC had to cut and restructure again. On both occasions the TAC was forced to downsize, leading to a huge drop in both staff and membership morale.

The TAC moved away from the district model to rebuild a wider branch membership base. Despite having less funding, since then it has been growing its membership and reach, strengthening the breadth and depth of its local voice as an independent advocate. By May 2014, it had grown its membership to 5,884 (4,576 women; 1,308

men), and by October 2015, it had 229 branches across the country.

TAC members nevertheless argue that they learnt a lot from the district experiment, in particular that by working in a very focused way they could build relationships with all the decision-makers and service providers, which made advocacy easier. If they spread too thin, TAC members may not be able to build and sustain the very relationships that enable them to make change happen. In particular, by gaining access to clinics where they conduct prevention and treatment literacy training, they get to know clinic management and staff, and they get access to information – such as drug shortages, personnel shortages, patient-client dynamics – around which they then advocate. In this way, playing 'insider' roles allows TAC members to play their 'outsider' advocacy roles more effectively (TAC Eastern Cape, 2015).

Impacts of funding on internal dynamics

Voluntarism versus employment

One of the difficulties for the TAC – as it began to give stipends to volunteers to undertake specific activities – is that newer members saw the organisation as a means to employment; some were motivated by the hope that volunteering would ultimately lead to a job. Many TAC staff and members commented on how this has undermined some of the quality of membership and caused massive internal tensions as members compete for jobs. In a context of very high levels of unemployment, this is a common challenge for MBOs and a tension that the TAC has to continuously navigate. The Global Fund money played a big role in shifting communities' perception of the TAC in the model districts – whereas volunteers had been the primary movers

for the TAC, now people were employed. When the funds went, the TAC was left having to re-establish the spirit of voluntarism.

Maintaining the power of elected representatives

The tensions within social movements created by funding are well known. The TAC is giving serious attention to the way in which funding has sometimes led staff to usurp the roles of elected leadership, and elected leadership to overly rely on staff (TAC, 2015b) – an issue termed 'staff creep' by a previous evaluation (Boulle & Avafia, 2005).

This mirrors the challenges faced by NGOs, who should play a role of accompaniment to community members – supporting their ability to engage in policy spaces in their own right – but frequently speak in their place (Eade & Williams, 1995). In the case of an MBO, while staff are themselves drawn from and living as community members, their role is to build leadership and participation among members rather than becoming the voice of communities. Yet at times, they can take over the spaces of members, or members can become too dependent on the staff of the MBO.

At the same time, having internalised a culture of challenging those with power, TAC elected officials are frequently dismissive of staff and organisational systems, something the CDRA evaluation notes as "innate and inherent to the activist/social movement identity of TAC." (Taylor et al., 2015, p. 23).

> "The aggression we displayed to government became the kind of aggression we displayed to each other [...] there was a culture of having to win the argument."
>
> *Sipho Mthathi, former TAC general secretary (Stephen, 2009, p. 171)*

Dual accountabilities

One of the complex dynamics facing MBOs which operate on donated funds is that they carry dual accountabilities – to their members who elect their leaders and to their donors (Taylor et al., 2015). The TAC set up its structures to emulate trade unions, where members are elected from local level and move upwards into national leadership. The difference between trade unions and the TAC, however, is that whereas workers' membership fees pay for union staff salaries and activities, MBO funds come from outside. In 2014, although the TAC doubled is membership fee from R10 to R20 annually (less than US$2), this was not enough to even cover one decent wage.

In order to better navigate this tension and strengthen financial and legal oversight, the TAC's national council – its highest decision-making body – in June 2013 established a formal governance board comprising a minimum of seven independent, well-qualified figures with specialist skills from the social justice sector, and three TAC office-bearers, including the chair of the national council and the general secretary; the third office-bearer in this first round is the representative of PLWHA on the TAC's national council (TAC, 2015a).

However, the tension remains that if an organisation takes funds for purposes not entirely in sync with its primary goals or its members' capacities, it will find itself torn between competing accountabilities.

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Costs of professionals

Another challenge when an MBO employs a large staff is that with staffing comes the need for expertise in human resources management and forms of bureaucracy that can stifle innovation (Seddon, 2007). The situation is exacerbated in a country such as South Africa with extreme levels of inequality, because those with professional training expect high remuneration – with some exceptions of people for whom the social commitment is all. Since MBOs usually do not want high levels of inequity in their pay structures, they frequently cannot afford the kinds of capacities they need not only to have the most efficient systems possible but also to meet the reporting requirements of donors. Some MBOs effectively outsource some of these roles by contracting financial management companies and similar.

This challenge also arises for other professional expertise such as research. Here the TAC has been more successful by keeping a small, hugely committed (and poorly paid relative to the NGO market) in-house team, which works in partnership

with others to secure the analytical capacity, legal capacity, and so on, that the TAC needs, without having to pay salaries at levels that would contradict its commitment to equity.

A related challenge pertains to shifts in leadership over time. As with most successful social justice organisations, the TAC was initiated by highly experienced activists – Zackie Achmat, Mark Heywood and Nathan Geffen in particular – who brought their strategic skills, their emotional fervour, their wide-spread networks and access to learning from both the anti-apartheid movement and the HIV movement globally into the process. The issue was a matter of life and death, and as the TAC captured the public's imagination in a David and Goliath fashion – taking on those with power and resources – donors competed to fund it. Once the initial goals were won – first the implementation of PMTCT and then access to ARVs for all HIV-positive people in need of them – donors started to give more attention to reporting and accountability and realised that the TAC had no institutionalised systems for routinely documenting its membership and its activities or for capturing achievements.

TAC leadership, however, managed to synthesise its experience into strategic insights shaping its next steps, without creating formal systems for M&E. As some of the initial leaders left the TAC to make space for 'leadership from below', they took with them this way of capturing change through synthesis as well as the educational qualifications they had built upon to master proposal writing and reporting.

The TAC is exemplary in the way it has nurtured and built leadership from below – exemplified by Vuyiseka Dubula who began as a treatment literacy coordinator in 2002 to become TAC's general secretary in 2008 – and this process has continued with its current leaders, General Secretary Anele Yawa, Deputy General Secretary Sindi Blose, and National Campaigns Manager Fredalene Booysens. All are held in high repute by TAC members and by the field. However, precisely because they came from the ranks and with a focus on HIV, they are high-quality political leaders; they are not human resources managers, finance managers, fundraisers or knowledge management system organisers. This is one of the reasons that led the TAC to establish a board of directors – to ensure that others with these skills would have oversight over the financial and management sides while the elected leadership had the political oversight.

The TAC is exemplary in the way it has nurtured and built leadership from below. However, precisely because leaders come from the ranks and with a focus on HIV they are high-quality political leaders; they are not human resources managers, finance managers, fundraisers or knowledge management system organisers.

Service provision for sustainability

One of the conundrums TAC members identify is that they developed curricula and trained health providers and NGOs as prevention and treatment literacy trainers but that some of those trained are now using that expertise to sell their services as trainers. Indeed, the TAC itself outsourced some of the training of PTLPs in the model districts, which was a source of concern to TAC members (Singizi cc, 2011). Why, they ask, did the TAC not get its own training programme accredited and offer to train others for money? While the idea was frequently discussed, it never happened – most likely because the capacities required to shift into a professional and sales mode had no 'fit' with the cultural style and capacities of an MBO. Nevertheless, TAC members express this as an opportunity for sustainability that the TAC lost (TAC, 2015b; TAC Eastern Cape staff leadership, 2015).

Monitoring for donor accountability rather than organisational learning

One of the major challenges the TAC has experienced is in managing funder reporting requirements. There is a fundamental mismatch between both the purpose and the skills of an MBO like the TAC, and the goals and accountability requirements of funders who fund service provision.

Some funders recognised this and provided funds or people familiar with funder reporting systems to help the TAC improve its monitoring and reporting systems. Neither of these approaches worked, however, because these funders assumed that funds or traditional M&E capacity were the problem. They did not fully recognise, or their interventions did not take account of, the fundamental mismatch in orientation between key donors' beliefs as to what the TAC should do and how it should assess its effectiveness, and the emerging and ongoing priorities of TAC members and partners. If anything, the various reporting systems that were initiated over time encumbered the TAC with increasingly unwieldy systems, as well as staff feeling patronised, distracted from their primary purpose and humiliated by the process.

"We spend hours and hours [*on*] writing the reports and then we're told they're not good enough. Why don't they interview us and then write it up the way they need it?"

(TAC Eastern Cape staff leadership, 2015)

This phenomenon is subject to increased deliberation by thought leaders globally. Onora O'Neill notes how the push for accountability that manifests in "detailed conformity to procedures and protocols, detailed record-keeping and provision of information in specified formats" and in "success in reaching targets" (O'Neill, 2002, p. 46) is damaging professional pride and integrity, and damaging

people's real work such that everyone becomes defensive. These circumstances, associated with "the audit explosion" (Mansbridge, 2014, p. 56) in the public and private sectors, apply also to activists who have to account to funders in ways that bear no relationship to their primary purpose of building "[*a*]ctive citizens who meet their duties [*and*] thereby secure one another's rights" (O'Neill, 2002, p. 32).

Activists learn through reflection (Healy, 2008). Both elected and staff leadership within the TAC are deeply reflective regarding which strategies are working well, which are not, and what changes are needed. Time is what is needed to capture member and staff insights and routinely reflect on them to ensure the TAC continues to operate strategically. Monitoring should support that process – information should be generated in a way that allows the organisation to use it in real time (Patton, 2012). Instead, TAC provincial staff write copious reports; PTLPs complete reporting forms every day (Singizi cc, 2011).

> "Paradoxically, certain accountability requirements can hinder organizational learning"
> *(Ebrahim, 2005, pp. 56-57)*

The reports are not set up in such a way that TAC staff and elected leadership can see progress and setbacks from one report to the next. There is data on numbers of condoms distributed and numbers of people exposed to prevention and treatment literacy education – reporting appropriate perhaps to a service delivery organisation. There is no capturing, however, of the lessons being learnt on what kinds of engagement are enabling people to let go of prejudice against PLWHA, or communities to take a stand against gender-based violence or homophobia, or are making clinic committees function more effectively.

In sum, the reporting does not incorporate issues at the heart of a membership-based activist organisation like the TAC. There is no place in the monitoring system for lessons being learnt on recruiting and retaining members; on the relationship between protest and one-on-one insider engagement; on what is making coalitions and partnerships work well and what is proving difficult; or on what makes the TAC's participation in government-civil society forums effective. These issues are simply nowhere to be seen.

While members and staff organisers are thinking about what is working and what is not and will discuss this at their own local meetings – when funds are available for such – it is not captured by the TAC's monitoring and learning systems. The leadership's activist mode leads them to use the TAC's national and provincial council meetings to discuss key challenges, but the gap between the
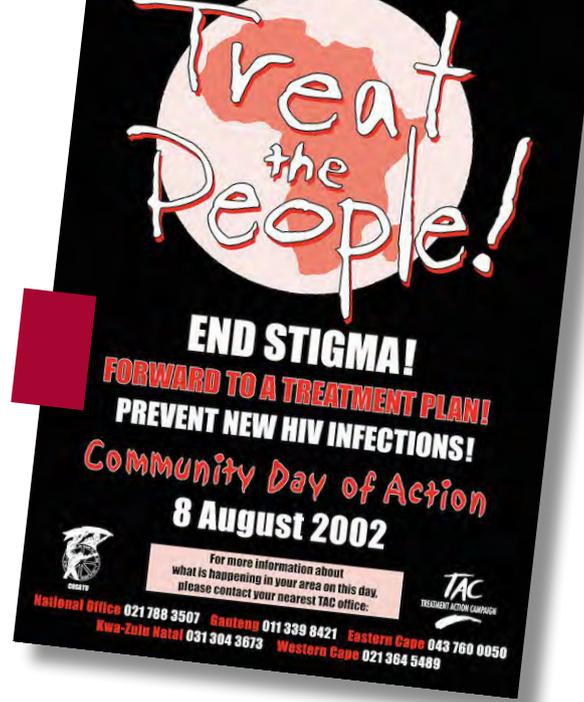
learning conversations and monitoring systems remains. Also, in recent years, the absence of adequate core funding has meant that forums (at national, provincial and district levels) are not held frequently enough to systematically draw lessons from members to take to national council, and to bring lessons from national council back to inform strategy processes with members at local level.

Significantly, the monitoring systems established with donor support also fail to monitor the TAC's internal development – numbers of branches as well as numbers and gender of paid-up members are haphazard with no way of comparing over the years.[21] There is no system for capturing reflections and lessons on, for example, ways in which the organisation is or is not building layers of leadership, or on the management of dynamics between staff and office-bearers. And there is no system for noting the organisation's responses to lessons that have been identified.

In other words, the pressure to report to funders against predictable deliverables has contributed nothing towards the TAC's ability to learn from its own achievements and challenges in a continuous reflection and learning cycle. In short, the TAC's

continued ability to innovate and learn happens despite its M&E system.

> "[...] present [*donor-TAC*] relationships are dominated by results, and 'management-by-objectives' based systems are not succeeding in achieving the developmental change that is required in TAC now."
>
> *(Taylor et al., p. 35)*

It should be noted that the TAC has some donors who provide core funding precisely in order to enable the TAC's ability to be adaptive and responsive. They would welcome the TAC developing an approach to monitoring appropriate to its empowerment and advocacy mission. However, because the TAC's primary donors until now have had project-specific reporting requirements, this has skewed the TAC's overall understanding of what monitoring and evaluation mean.

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[21] One TAC donor has given funds specifically for this exercise, which the TAC is currently finalising to have a definitive map as the basis for its current strategy and organisational restructuring process.

4

Conclusion: learning from the experience of the Treatment Action Campaign

The range of lessons that can be drawn from the TAC's experience could fill a book. This chapter picks up some of the themes particularly related to membership-based social justice groups operating within constitutional democracies.

Lessons for membership-based organisations

Membership and leadership motivation

When an MBO is engaged in enabling people to save their own lives, it is not that surprising that it creates a high degree of loyalty. This begs the question of how MBOs create this powerful sense of relevance on issues that are not quite as much a matter of life-and-death. It talks to the need for groups to make a case that engages potential members in a deeply personal way even when it is about broader issues such as protecting the environment or promoting the rights of refugees.

What is clear from the TAC's experience is that leadership will emerge from people who are deeply personally motivated by the issues, irrespective of whether they are directly affected; the desire

to be part of a process of social change is the key motivator. Members who join to resolve short-term personal issues, or in the hope of accessing resources or power, are unlikely to develop into effective and ethical movement leaders.

> Leadership will emerge from people who are deeply personally motivated by the issues, irrespective of whether they are directly affected.

The TAC has a key lesson to share in the importance of building and using evidence to support MBO claims. It shows that gathering and publishing evidence is not enough. One needs effective methods to actively engage with members, communities or partners about the new information in ways that build their knowledge, motivation and skills to take action. Building members' access and ability to use well-researched information is key to the creation of individual and organisational power. As reflected in the literature, it is when information is linked to high levels of individual motivation that people change their actions. However, to do so in a smart and strategic way, people also need the requisite skills. The TAC's ongoing training for membership has incorporated all three aspects (knowledge, motivation and skills) and members' activities in turn further motivate them.

Continuous membership and leadership development

That said, new members come in, new information is constantly generated, and the political, cultural and economic contexts in which MBOs are working are often shifting around them. This means that MBOs have to invest in continuous member education. There is no moment when an organisation is strong and can assume that strength will last. Membership and leadership development has to continue throughout.

> There is no moment when an organisation is strong and can assume that strength will last.

The TAC also provides a good example of leadership succession and building leaders from grass roots to run the organisation. In some ways, because MBOs elect their leaders there may be a greater likelihood of relatively frequent successions, but the idea of succession needs to be an integral part of the planning of MBOs (and indeed NGOs). Even in the TAC's case, the initial 'brand' was so closely associated with its early leaders, in particular Zackie Achmat, that it took a long time to build public and donor confidence in the new elected leadership. Anticipating this and ensuring that people in diverse leadership positions, including second-level leadership, gain management and leadership skills as well as exposure to diverse forums and relationships with key partners is an essential dimension for organisational culture to enable smooth transitions.

It is important, however, to distinguish leadership from management. The TAC is good at building leadership – people who can inspire members, adapt in shifting contexts and develop innovative strategies – but leaders are then expected to become managers. The task of management and the possibility of sustaining organisational capacity would be substantially improved if emergent leaders were provided opportunities for training in management skills and given sustained support in building these skills over time.

Institutionalising ways of learning and recording achievements

When a group is small, activists strategise together, take actions together and learn from their successes and failures together. If they grow so that members are operating in different places, or there are simply too many to easily and regularly reflect together, the MBO has to work out how to institutionalise its ways of working and learning. How do lessons learnt from a strategy in one place translate into other contexts where members are trying to address similar issues? The trade-union-like structure of the TAC ensures that local-level representatives – in the form of branch chairpersons – meet regularly (when funding allows it) for this purpose and that their representatives in turn – provincial chairpersons, along with paid provincial coordinators – meet to bring together the analysis of current contexts in diverse places into a single analysis, and to bring together lessons from diverse strategies into national, overarching strategies. It is there that they also draw out lessons from their efforts, albeit not always systematically. Having strong internal systems for talking and reflecting on strategies and lessons is essential as an MBO grows.

Having simple ways of capturing achievements and lessons on what works well and what does not (in writing and in formats that allow one to see changes over time) is also essential for maintaining organisational and strategic strength. It creates a supportive environment for staff and member development, for recognising achievements and identifying how to address challenges. Doing this well also enables an MBO to rely on its own

processes and analyses, including its ways of recording its achievements and learning, which puts it in a position of strength when navigating and deciding upon external partnerships or relationships with funders, and when negotiating how it will communicate its activities and outcomes to them.

Having strong internal systems for talking and reflecting on strategies and lessons is essential as an MBO grows.

Respectful member-staff relationships and organisational culture

If an MBO decides to grow its staff, it needs to prepare its members and leadership to think about what relationships it wants to develop between staff and members, including elected leadership, at all levels.

One of the consistent tensions identified in recent TAC evaluations has been between the modes of decision-making of elected political leadership and of staff. Another tension identified by TAC staff is that as the TAC increased its staff complement, volunteers often looked to staff to take on roles that previously and properly belonged to TAC members and elected leadership.

If an MBO, particularly of members who are poor or politically or socially marginalised, reaches the point that it requires high-level professional skills – in financial management, donor engagement, communication or M&E – how will the organisation value this expertise and authority but ensure that it is fully in tune with the organisation's overall values and purpose?

Mansbridge suggests that the key is to put careful attention into selection rather than setting up a culture of distrust and sanction after people are employed (Mansbridge, 2014). This is certainly the starting point – finding people with deep commitment to the issues and self-motivation is essential. However, in addition, the MBO needs to be very conscious of how it will both model and monitor the development of these relationships so it can continually improve them. In contexts where MBO members build their confidence and capacities for confronting those with power, it is essential that they recognise the difference between external advocacy and internal relationship-building, particularly where elected leaders have political authority that gets mediated by the authority of professional staff.

Another complication that staffing up often brings for MBOs is the question of equity in salary structures, and of having to set up human resources policies often for people who have an activist

orientation in which they are driven by external needs and are unlikely to have much interest or experience in the more repetitive requirements of organisational systems. Getting systems right takes both thought, ability to draw on ideas and innovations from others, and ability to reflect in an ongoing way on what is working and what is not. Importing corporate systems into an MBO is unlikely to work; similarly, sticking with a responsive, crisis-driven activist style cannot work as an organisation grows and has accountabilities not only to members but also to donors. Finding the right balance is a challenge.

Community accountability structures: 'invented' and 'invited' spaces

National legal frameworks frequently incorporate mechanisms for 'community accountability', that is:

> […] *the ability of communities (and, for the purposes of this review, primarily local communities) to hold governments, funders, bureaucracies and service providers accountable to them for the provision of services and opportunities that meet basic rights.* (Westhorp et al., 2014, p. 11)

However, these 'invited' spaces can only realise their intended role if they are well resourced, and if community members are actually elected representatives of constituencies and have the information and confidence they need in order to speak truth to power. It is for this reason that democracies require additional forms of engagement and monitoring, including spaces invented by activists to hold the public sector accountable. The SSP (Stop Stockouts Project) is one such mechanism, as are the multiple coalitions through which the TAC works, such as the ECHCAC (Eastern Cape Health Crisis Action Coalition). In these ways, civil society groups generate their own evidence base, consolidate demands, build alliances, and use these to push the state to engage civil society and to take action.

> Democracies require additional forms of engagement and monitoring, including spaces invented by activists to hold the public sector accountable.

Success creates its own pressures

As an MBO builds its reputation, it will face new external challenges in terms of maintaining its coherence.

Funding relationships

When an MBO becomes well known for the power of its grass-roots base and the efficacy of its strategies, others will be drawn to it. This is how it will grow its membership, build partnerships and alliances, and strengthen its claims for social justice.

However, in this process, organs of government, funders and other civil society organisations may all see the MBO as an entry point to achieve their own ends. This too can be a significant positive outcome, but it can also bring offers of support that do not fully fit with the MBO's values or with its purpose. This has been one of the major challenges faced by the TAC, which reorganised itself to fit with donors' desires for service provision, only to find that donors would not sustain this funding; in the meantime, this reorganisation had diverted the TAC from its primary advocacy purpose.

At the same time, as the MBO grows, its need for staffing and therefore for funding may grow, unless it has managed to develop some sustainable mechanism for funding along the way – for

example, MBOs with a middle-class membership may be able to source substantial funds from members and the broader supportive public.

If the MBO decides to increase its reliance on funders, it needs to develop its own understanding of the funding terrain. It will need to analyse the values underlying each funder's interests, recognising that there are often distinctions between the values and ways of working of a programme officer, and those of the funding institution that person represents. It will need to understand how that funder understands the MBO's work and purpose, and what sort of monitoring and learning systems the funder requires. This will help the MBO work out whether taking funds from a particular funder or NGO intermediary will help or hinder it in achieving its overall goals; and it will give the MBO the confidence to make its case regarding what kinds of support it needs (money, expertise, linkages with the field) and what kinds it does not; what kinds of reporting will strengthen its own learning and what kinds will not be helpful to the MBO or may even make demands inappropriate to its goals or capacities.

Equitable partnerships with other civil society groups

Aside from funds, MBOs usually need other resources that they can access through partnerships – researchers, people who can translate technical knowledge in ways that are meaningful to members, service providers who can bring in perspectives and knowledge of how the systems that the MBO seeks to change actually work, people who have access to key deliberative or policy-making spaces, and so on.

Here too, the more relationships of trust that can be built over time – based on an explicit understanding of what each group brings to the relationship – the less tensions are likely to develop in the work. That said, each individual and group will have explicit or implicit values and perspectives, based on their personal histories and their training. MBOs need to be aware that who they choose as advisors will influence the type of information and analysis they receive. There are few simple truths or facts. Hence it is important to explore to what extent potential partners are able to take account of social and economic power relations in their thinking and experience.

In this case study, the dominant paradigm of scientific enquiry focuses on technical interventions to address HIV transmission despite the fact that HIV transmission has social determinants which influence if and how technical interventions work in practice. In addition, potential interventions or demands always have to consider the extent to which they take account of inequitable power relations in society.

> *"Pathologies of power underlie many health problems. Hence promoting human rights should be key to health interventions."*
>
> *(Yamin, 2015)*

Finally, the larger the MBO, the harder it becomes to ensure deep participation at all levels in all major decisions. Nevertheless, a lesson from the TAC is that to the extent that opportunities arise for partnerships at provincial or local levels, they need to be conceptualised by those who will be making the partnership work rather than by staff working at the national (or international) level and then being handed over as an already final commitment that those on the ground have to deliver on.

This is of course also a lesson for NGOs and civil society or donor intermediaries. MBOs will frequently look like a gift to such groups because, through an MBO, an NGO can achieve its objectives, it can 'reach the grass roots' or 'the field'. It is essential that in negotiating such relationships, the power, reach and capacities brought by the MBO are clearly named, including making explicit that the MBO and its members have decision-making power, and what the limits of their power and that of the partner NGO are. Frequently, NGOs and intermediary groups raise funds in the name of 'communities' or even of specific MBOs, but they do not engage the MBOs while conceptualising the proposals; yet they make massive demands of the MBOs for compliance. In addition, NGOs and intermediaries sometimes take as given that MBOs have the institutional capacities required, and fail to provide the human and financial supports that the MBOs need for the relationship and work commitments to be fully realised.

Democracy requires both trust and sanction

In the current South African context there is a growing tone of 'them and us', in which questioning government is cast by some members of government as unpatriotic. Similarly, some donors fear groups that are 'political'. To effectively push for social justice, MBOs need to position themselves so that they can be fluid in their strategies, both engaging existing 'invited' spaces, and inventing spaces as needed.

In the context of a constitutional democracy, as opposed to a dictatorship or authoritarian system, MBOs should engage the state or other powerful players when it is possible to shift their perspectives or even to support them in solving problems. The TAC and MSF's contribution to sorting out the Mthatha Medicines Depot in the Eastern Cape, as seen further above in box 2, is a shining example of this.

In some situations, MBOs are able to build relationships of trust and to use these to support government in improving services. On the other hand, MBO accountability is to its members, and MBOs have a responsibility to use all possible means to bring issues to the attention of those with power, including naming and shaming them publicly – that is, social sanction – when MBOs have not been able to garner positive responses to their efforts to engage those with power on the basis of trust and mutual respect. The TAC's marches, sit-ins and litigation all attest to the effectiveness of these approaches. One of the TAC's founders also emphasises that litigation does not have to disempower groups on the ground, assuming relations of trust and mutual respect between legal groups and MBOs.

An important point to stress (as this is often an argument made against the use of law) is that the TAC did not disempower its members through use of law, or surrender its campaigns to lawyers and legal process. It worked closely with the AIDS Law Project, a specialist legal NGO[22], and demonstrated that mobilisation and legal action can interrelate and catalyse each other. A political campaign can give rise to a court case; a court case and the unfolding of different stages of the legal process can sustain a series of demonstrations and a rising movement. (Heywood, 2015, p. 324)

Lessons for funders

Donor-supported, not donor-driven

The TAC continues to have the support of a wide range of donors who have stood in solidarity with its members and goals, some since it first began. Donors meet with the TAC regularly to identify opportunities and challenges and have in different ways given the TAC phenomenal support.

Some of the TAC's funders share its commitment to social justice and have an activist orientation so that the TAC's approaches are entirely within

their comfort zones. They provide the TAC with core funding to use as it sees fit and to report on retrospectively.

Other funders share the TAC's goals but are less comfortable with the trust-based funding model that MBOs need in order to have the agility, flexibility and adaptability to be able to find innovative ways of moving their agenda in a constantly changing political environment. Such funders have needed the TAC to commit to specific strategies and intended outcomes, although they have also been willing to renegotiate these if conditions suggest the need.

A third group of funders have been able to fund the TAC only against predetermined results that it has to achieve. In particular, in keeping with the global push for government to outsource its work to NGOs, many donors and donor intermediaries have looked to the TAC to become a service provider, where its achievements are measured through such indicators as numbers of condoms distributed and numbers of women, men or youth who have attended training rather than in terms of outcomes appropriate to an advocacy organisation (see more on this below). In this context, the TAC has had to fit itself into these donors' institutional requirements – or to say no to the funding,

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22 The AIDS Law Project broadened its remit and became Section27 (S27) as referenced earlier in this report.

something the TAC is only now starting to learn.[23]
This situation is not only problematic for the TAC
but also problematic in terms of understanding that
rural poor people need a functioning health system,
and that civil society organisations cannot become
Band-Aid; what is needed is the strengthening of
health system capacities and enabling the TAC
to continue to support people who are otherwise
disempowered or stigmatised to build their agency
and hold government to account.

Support collaboration

Social change is achieved through multiple
strategies by diverse players. This means funders
need to recognise that 'their' grantees, assuming
solid strategies and a conducive environment, will
contribute towards such changes but are most
unlikely to be the sole players. The TAC's story of
partnerships at every level attests to this. What this
means is that donors need to reward grantees who
acknowledge the contribution of others and even
reward collaboration between groups.

"Garnering recognition for
organizational achievements
and building organization brands

are considered critical for
fundraising success and, in turn,
organizational sustainability. It
should therefore be no surprise
that humility is not the norm in
the nonprofit sector. To harness
the tremendous potential of
networks, all nonprofit leaders
must let go of conventional
wisdom and shift their focus
from organization-level goals to
network-level impacts."

(Wei-Skillern & Silver, 2013, p. 122)

Funding social change: be flexible and bet on grantees

It is now fully understood that social change, and
particularly advocacy for social justice, takes place
in contexts that are constantly changing, where
windows of opportunity open and close, where
there are multiple players and wide-ranging ideas
as to how to understand social problems and their
potential solutions.

Changes in political context require changes in strategy

Funders whose goal is to support efforts to
foster social justice usually recognise that this

[23] As a matter of policy, the TAC has not taken money from
government or the pharmaceutical industry, so these
donors are not even considered in the comments here.

requires a mix of strategies, some of which may be confrontational. This is because, at times, working 'inside' the system cannot deliver results, and so civil society groups need to mobilise public voice and pressure for change using whatever strategies will have maximum impact. It is a question of context.

A key lesson from the TAC is its ability to read the political context and shift strategies accordingly. The TAC has used every possible opening to engage directly with the DoH and support its efforts to strengthen the health system and health service delivery. But at times, it has had to build a strong public voice for action, occasionally to litigate. As this report shows, health care providers and managers might value the TAC's ability to raise outrage about the situation; but they might also ignore the TAC or be hostile.

Donors need to recognise that reading the political context well means shifting strategies accordingly and being able – sometimes simultaneously – to engage the system even while publicly shaming it. Funders who are only comfortable with 'insider' strategies are not well positioned to fund social movements and MBOs that will speak out as necessary.

> Donors need to recognise that reading the political context well means shifting strategies accordingly and being able – sometimes simultaneously – to engage the system even while publicly shaming it.

This level of strategic capacity is often only possible because of the mix of skills and relationships among diverse organisations working collaboratively. For this reason, funders who focus on supporting marginalised communities or grass-roots groups

need to assess whether the overall field includes the kinds of support organisations that enable membership-based grass-roots groups to be effective – that is, groups providing legal advice and litigation, producing the necessary evidence, and so on. If no other donors are funding such groups, then 'grass-roots' funders may need to rethink their strategies because MBOs will seldom achieve their goals alone.

The need to bet on grantees

Highly skilled activists are constantly shaping strategies to widen the base of support and build alliances around their issues and proposed solutions; building or drawing upon evidence; creating spaces to influence the visibility of their issues and the perspectives of the public and decision-makers on them; and engaging with those with power where possible (Klugman, 2011). This is a messy and unpredictable terrain, characterised by complexity and intersecting systems with multiple elements and multiple relationships (Williams & Hummelbrunner, 2011).

> "It is often assumed that controls and performance-accountability systems ensure quality impacts, when in fact shared values and trust among funders, nonprofits and beneficiaries can actually lead to superior results."
> *(Wei-Skillern & Silver, 2013, p. 122)*

MBOs and NGOs advocating for social justice need funders who understand this complexity and are willing to give them the resources to do what they need to do and with no guarantees. Indeed, they need donors who welcome organisations experimenting and learning from what has worked well and what has not. They need donors who understand that strong organisational systems as

well as investment in staff and member learning and development, and in building and sustaining a conducive organisational culture are all key to organisational sustainability and to the possibility of MBOs continually generating new layers of members and leadership who can read the environment and engage it strategically. Social justice MBOs need donors who are willing to take a bet on the organisation, based on its record and based on trust.

Core funding for strategic organisations

Social justice MBOs need core funding – not for projects, not for one-off interventions, but to enable their organisations to function effectively and have funds for strategically proactive and responsive initiatives. They need to know that there will be funds coming in from year to year, so that they can operationalise long-term strategies and not have staff in a perpetual state of anxiety about the permanence of their positions, or members never knowing whether they will be able to continue initiatives they have started, not to mention using up precious leadership time in the administrative complexity of repeat funding applications every year.

Key to supporting activist styles of mobilisation and organising is the recognition that social change is unpredictable. The art of funding this kind of work is to identify groups who have a clear vision, strong leadership and strong strategies, and then fund the organisation rather than a project to enable them to also build their organisational capacities, governance and systems. It is about trust.

Fund organisational development and sustainability

Implicit in all of these issues is the importance of social justice groups continually building and renewing their internal leadership capacity. Yet often, focusing internally seems like an indulgence

in context of the pace and depth of social issues that need addressing.

> "Funders tend to consider grantee staff as part of "overhead" – a cost to be avoided as much as possible. [...] talent [*is*] a primary asset for organisational success. [...] People are the most important asset driving performance, impact, innovation and sustainability in the social sector."
>
> *(Stahl, 2013, pp. 41, 42 & 47)*

Funders can be critical in validating organisations spending time and funds on their own development and on sustaining organisational systems – for example, financial management, board and staff policies, or routine reflection and learning around the effectiveness of strategies. They can also be critical in asking questions about leadership development and encouraging use of their funds for one-off and ongoing leadership development; and in promoting the importance of succession planning, making clear that "strong organizations plan for transition" (Summers & Honold, 2013, p. 45).

It is lack of attention to these issues that has made it very difficult for TAC leadership to cope with the vagaries of nation-wide staffing and diverse funding paradigms and requirements.

Assess actual outcomes

Contemporary thinking on evaluation in complex environments is increasingly recognising that even when strategies and activities are clear, there is no way of predicting their outcomes. Consequently, the best approach to both learning and funder accountability is to capture outcomes once they

have been achieved. One can then assess them against the theory of change that the MBO is using to see whether actual outcomes are those they hoped for, and which strategies are proving most effective (Britt, 2013; Wilson-Grau & Britt, 2012).

This is a trust-based approach to accountability rather than one of sanction. The latter requires groups to commit in advance to very specific deliverables and to account for their failures should they not achieve them. To ask MBOs with an activist mission to predict in advance through a logical framework or similar what they will achieve is to engage in astrology. To ask such groups to then report against those predicted achievements will put them in a straightjacket to a point that they may lose their ability to pursue their mission.

> To ask MBOs with an activist mission to predict in advance through a logical framework or similar what they will achieve is to engage in astrology.

For funders to fund groups to pursue their strategies, capture their outcomes and learn from them assumes that such groups have high levels of organisational reflectiveness and capacity as well as the ability to document these in ways that support ongoing learning and reporting. This is where funders can provide critical support to MBOs.

In the TAC's case, a number of donors recognised that it could not manage its monitoring obligations, so they offered a mix of funds to hire M&E support, or of people to set up M&E systems. However, such support frequently lacked an understanding of how to capture outcomes and instead reinforced the very problem by trying to fit a flexible, community and politically engaged organisation into a set of predetermined boxes. As the stories above indicate, the TAC's efforts to deliver within these systems have left staff disempowered and funders disgruntled.

What the TAC needed was support in establishing a system for capturing outcomes that were tightly linked to what TAC members and staff were continually trying to achieve. This could include outcomes like:

- improvements in the ability of TAC members and community members to ensure they get the treatment they need at clinics and to report when clinics do not have the facilities or medicines required
- improvements in the ability of TAC members to speak in public forums and to engage in constructive discussion with health care providers and managers

- increase in the TAC's access to and engagement with policy forums or increase in their actual engagement with policy-makers or service managers at all levels – clinic, local, provincial and national
- increased visibility of the issues – in media coverage or through public opinion leaders speaking out
- improvements in law, jurisprudence, policy or regulations, or in actual service delivery at all levels – clinic, local, provincial and national (Klugman, 2011).

Some of these are easy to measure – for instance, attendance at a policy meeting, or a court victory; others are not. But if organisations develop a culture of routinely debriefing on their strategies and activities they will capture substantial information that will let them assess how well, if at all, their strategies are working – this is what evaluators term 'harvesting outcomes' (Wilson-Grau & Britt, 2012).

"Intelligent accountability, I suspect, requires more attention to good governance and fewer fantasies about total control."

(O'Neill, 2002, p. 58)

Implicit in this is that organisations have time and funds to bring their members together for learning. In the last few years, the TAC has battled to find such funds, having more resources for external projects and for engaging communities, for example, than for sustaining its own members' development and internal learning.

Donors can support MBOs in imagining creative ways of institutionalising their learning, because donors have so much exposure to approaches being used globally. They can link MBOs to others to learn from their experience. They can also ensure that MBOs have the sort of funding that enables institutional development of this kind.

The Treatment Action Campaign as of October 2015

Despite its continuing successes and inspiration to movements nationally and globally, the TAC has not been able to generate resources to sustain its size, and it has not had the space to take its members through a process of re-envisioning and reshaping itself after the district model experiment. The organisation is now rethinking its structure and ways of working, embarking on a major restructuring process to take it into its next phase

and seeking to do so in a deeply reflective manner even while, as it faces this crisis, it continues to pursue its national campaigns and local strategies.

This report tries to capture some of the dynamics and power of the TAC's experience of local organising and to draw lessons from that experience, lessons deemed not only useful to other MBOs, NGOs or funders but also to the TAC as it reshapes itself in ways that are true to its membership and its vision. Hopefully, lessons from its past will enable it to re-imagine how it will operate with less resources; how it will continue to build its political and strategic sophistication; how it will build a culture of creative and respectful tension between its staff and its elected leadership; and how it will extend its tried and tested approach to shaping its initiatives from the lived experiences of its members on the ground.

A number of studies, notably the *South African National HIV Prevalence, Incidence and Behaviour Survey, 2012* (Shisana et al., 2014) and *The People Living with HIV Stigma Index: South Africa 2014 – Summary Report* (Human Sciences Research Council, 2015) indicate that a concerted effort is essential to continually build the understanding of individuals and communities as well as their commitment to take action to prevent and treat HIV, TB, cervical cancer and related health problems, and to create an environment that promotes gender equity and sexual and reproductive rights and does not tolerate gender-based violence – issues that are important in their own right but also essential for increasing the effectiveness of HIV prevention efforts.

What this report makes clear is that a bottom-up membership-based organisation such as the TAC can play roles no other groups can play in this regard. However, to be able to do so in the current era means that it must reposition itself. The TAC needs to have the strength in its staffing systems and in its culture to be able to build up the breadth and depth of its membership and their elected leadership to take on these challenges in a sustainable way.

5
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