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# Technologies of 'participation' and 'capacity building' in HIV/AIDS management in Africa: four case studies

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## **Technologies of 'participation' and 'capacity building' in HIV/AIDS management in Africa: four case studies.**

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### **Introduction**

Sub-Saharan Africa carries the heaviest burden of HIV/AIDS. Marginalised groups are particularly heavily affected. Women and young people carry the highest burden of infection. Poor people and people in rural areas have the least access to health and welfare assistance. Millions of people are dying of what is in principle a preventable and treatable disease – often in conditions of almost unbelievable suffering – with no medical help at all. Against this background, people are increasingly referring to lack of ‘political will’ as the reason for the continuing grip of HIV in Africa. This is fast becoming a buzzword in debates. In the Executive Summary of the 2006 UNAIDS report, which pulls together the state of the art deliberations of a range of international agencies, the final sentence reads: “We know what needs to be done to stop AIDS – what we need now is the WILL to get it done” (UN AIDS, 2006, p.24).

Discussions of political will in the media and the academic literature often centre on ‘corrupt’ or ‘incompetent’ African leaders (Lewis, 2005), leaders of wealthy countries that contribute too little to international aid efforts (Attaran and Sachs, 2001; UNAIDS, 2008), or to economic actors in profit-hungry pharmaceutical companies (Bond, 1999; Heywood, 2002). This focus is part and parcel of a tendency to identify the operations of ‘the political’ in terms of the words and actions of high profile leaders. However, Foucault (1995) emphasises that power operates in a complex and multiple range of sites and channels, and should be investigated in the least obvious as well as most obvious of places. Following his

advice, this paper is part of the author's wider project of highlighting the multiple sources and operations of power that shape responses to HIV/AIDS in sub-Saharan Africa.

Elsewhere we have examined the way in which power operates at a micro-level in remote rural communities in South Africa, looking at how relationships of gender (Campbell *et al.*, 2006; Campbell *et al.*, 2007a) and generation (Campbell *et al.*, 2007; Campbell *et al.*, 2008) undermine the likelihood that poor rural people will make optimal use of both formal prevention, treatment and care services as well as informal sources of social support. We have also looked at the way in which the functioning of traditional leadership structures serve to undermine such access (Campbell and Gibbs, 2008a), and at factors that limit the responsiveness of district-level health and welfare agencies and personnel to the needs of the local communities they claim to serve (Nair and Campbell, 2008). At the symbolic level, we have examined the way in which representations of the HIV/AIDS struggle in the South African media serve to mask and undermine the massive role being played by poor women and households in shouldering the burden of HIV/AIDS (Campbell and Gibbs, 2008b).

The aim of this chapter is to examine the role of highly respected international development agencies, supported by armies of well-funded academics, in continuing to support and fund ineffective HIV/AIDS management programmes in Africa. How do these actors and agencies serve to contribute to the perpetuation of power inequalities in the guise of benevolent assistance? We address this question through discussion of four case studies of southern African care and prevention programmes in which we examine the contradiction between the rhetoric of 'community participation' and local 'capacity-building' – with all its implicit promises of empowerment and positive social change for marginalised people – and the reality of programmes which claim to implement these strategies.

Billions of dollars of international development aid have been poured into HIV/AIDS management in Africa. There have been some encouraging reversals in the epidemic's hold in some countries e.g. Uganda and Zimbabwe (UNAIDS, 2008). However, there is little evidence that HIV/AIDS interventions have played a role in this. In fact in a recent randomised control trial of state-of-the-art interventions rural Zimbabwe, it was found that HIV/AIDS incidence was actually *higher* in the intervention sites that had been targeted by prevention programmes, than in the control sites that had not (Gregson *et al.*, 2007). A key reason for the disappointing outcomes of many programmes is their failure to resonate with the perceived needs and interests of target communities (Campbell, 2003). As the UN AIDS (2006) report cited above acknowledges: "Community involvement is essential if any of our grand plans are to be achieved" (UN AIDS, 2006). Yet agencies all over Africa are failing to facilitate proper community involvement in AIDS programmes – communities are systematically excluded from meaningful participation (Gruber and Caffrey, 2005; Rau, 2006).

Despite a great deal of international and regional policy rhetoric (UNGASS Declaration, 2001; African Union, 2006; South African Government, 2007) about the importance of community participation in AIDS efforts, the bulk of HIV/AIDS interventions are biomedical and behavioural in nature, targeting individual knowledge, skills or disease states, and imposed on passive communities by outside experts (Waldo and Coates, 2000; Parker *et al.*, 2000; Parker and Aggleton, 2003). Within the specialist HIV/AIDS prevention literature, programme evaluations focus overwhelmingly on technical aspects of programme design and delivery, and characteristics of the target audience (Kippax and Van de Ven, 1998; Cornish and Campbell, 2008). The little attention that is given to the social relations that frame these interventions tends to focus mostly on the indigenous social relations in which programme beneficiaries are located, paying less attention to features of the health programme itself that might have undermined its effectiveness. Within the HIV/AIDS literature virtually no attention is given to

the role which implementing organisations play in facilitating or hindering the effectiveness of HIV/AIDS programmes.

Development anthropologist David Mosse (2004) argues that programme failure is invariably constructed in a way that blames everyone except for the development agencies that implement them and the so-called 'expertise' that informs them. He comments that analyses of development failures overwhelmingly lay the blame on events, situations and people outside of the framework of development expertise and authority. In so doing, the inputs and actions of academics and development agencies are distanced from any responsibility. Ironically, rather than leading to critical reflection and change in the views and practices of experts and agencies, failures are explained in ways that reinforce the very agency-community relationships, and the very systems of expertise within which health projects are entangled.

### **The social psychology of participation**

Our particular interest in the importance of community participation in HIV/AIDS programmes is driven by our starting assumptions about the social psychological benefits of such participation (Campbell and Jovchelovitch, 2000). Here we explicitly position social psychology in opposition to health psychology. Health psychology tends to take the individual as its unit of analysis. Social psychology, by contrast, tends to take the individual-society interface as its unit of analysis. Mainstream health psychologists have been accused of playing an active role in driving the HIV epidemic through their persistent claims that HIV/AIDS can be prevented through behaviour change programmes targeting individuals (Waldo and Coates, 2000). Whilst this might be the case in relatively affluent and educated populations in high income countries (Johnson *et al.*, 2002), this promise ignores the inescapably social dimension of the epidemic in many Sub-Saharan African contexts.

Writing about AIDS in Africa, French anthropologist Didier Fassin refers to AIDS as the “embodiment of history...the way in which individual and collective histories are transcribed into individual and collective bodies.” (Fassin, 2002: 65). In Africa, power relations of poverty, age and gender make it very difficult for many to protect sexual health. Ideally the epidemic would best be addressed through macro-social change leading to the redistribution of economic and political power, both locally and globally, but these are long-term goals, unlikely to be achieved in near future. In the medium-term, such efforts should be supplemented by the facilitation of programmes and processes that serve to buffer or ameliorate the impacts of social inequalities on peoples’ health, through facilitating ‘participation’ by affected communities – viewing communities as one of the many sites through which social inequalities are imposed on individuals who respond in varying degrees of submission or resistance (Howarth, 2001; Campbell, 2003).

What kind of community participation is most likely to empower marginalised groupings to make the best use of prevention, care and treatment services, to change their own behaviour, and to provide support to others with HIV/AIDS? Participatory health programmes should provide people with the skills and knowledge they need to respond effectively to HIV/AIDS. These include not only directly AIDS-related skills in areas such as participatory peer education or home nursing, but also the development of local capacity in programme leadership and decision-making, so that people can play an equal role in shaping, implementing and evaluating programmes. People are most likely to feel they can take control of their health-related behaviour if they have experiences of being in control of other aspects of their lives (Wallerstein, 1992). Participation in programmes that are seen to elicit and reflect community views and needs, and to include community members in leadership and decision making, is a key strategy for achieving this. The development of such skills and capacity amongst local people enhances the likelihood that grassroots communities will feel a greater sense of collective ownership of the problem of HIV/AIDS, as well as a sense of

confidence that community members have both the individual and collective skills necessary to contribute to its management.

Ideally programmes should provide people with safe social spaces in which they can translate alien medical information into discourses that make sense to them and action plans that can be realistically implemented in the context of their lives. Such social spaces provide the possibility for critical thinking and dialogue (Freire, 1970; 1973). People are most likely to develop health-enhancing attitudes and behaviours when they have opportunities to engage in collective dialogue about the obstacles to behaviour change, and to brainstorm ways in which they might – individually and collectively – resist such obstacles. Interventions that take account of target groupings' understandings of the nature of a problem, and that strive to involve local people at all stages of devising and implementing strategies are most likely to resonate with the perceived needs and interests of the target groupings whose attitudes and behaviours they seek to change.

Such spaces also provide people with a sense of solidarity, common purpose and collective responsibility for contributing to the fight against HIV/AIDS. These hopefully serve to counter a sense of fatalism in the face of the enormity of the problem, and a passive sense that the problem is the exclusive responsibility of outsiders (e.g. from government or NGOs) – and that local individuals and groups have no role to play.

Finally, programmes should provide the opportunities for community members to identify and build relationships with outside support agencies – in the NGO and public sectors for example – that have the political and economic influence to assist them in achieving health-related goals. Marginalised communities often lack the power to tackle serious health problems without substantial outside support ('bridging social capital').

Elsewhere we have argued that effective participation should result in the development of six psycho-social characteristics of what we call an 'AIDS competent community context'. This is a social environment in which grassroots people are able to work collaboratively in supporting one another to achieve behaviour change, stigma reduction, support for people with AIDS and their carers, support for volunteers and health workers responding to AIDS, and the accessing of health services and welfare grants where these exist. The six characteristics include: appropriate knowledge and skills (including both AIDS-related and leadership skills), social spaces for dialogue and critical thinking, a sense of solidarity and common purpose, a sense of ownership of the problem and responsibility for tackling it, a recognition of individual and collective local strengths for leading and implementing a local response, and strong bridging relationships with outside support agencies (Campbell *et al.*, 2007b).

From a social psychological perspective there is no doubt that concepts and strategies of participation and local capacity building have a crucial role to play in the development of AIDS competent communities and in enabling the success of health and social development efforts in marginalised contexts. However the paper will illustrate how these concepts may be hijacked by health and development experts, who pay lip service to them in programme and grant proposals, but fail to implement them effectively in practice. In this respect, the hijacked concepts of participation and capacity building could arguably be said to serve as disciplinary technologies (Foucault, 1977), implemented by the international development apparatus and part and parcel of the "procedural applications of power ..... through institutionally operated systems of intelligibility and control" (Hook, 2007: 216). According to Hook (2007: 216), a technology may be understood as "an expert system comprised of a discrete set of applied skills, practices, knowledges and/or forms of specialist language, used, whether by experts on deviant subjects, or by individuals on themselves, as means of achieving objectives of increased mastery or control".



## CASE STUDIES

Against this background, this chapter looks at four international development programmes the author has been involved in evaluating in various contexts in southern Africa. Each project explicitly claimed to be community-led and community-owned, and was driven by an 'empowerment via participation' methodology. The aim of this discussion is to focus on some of the subtle ways in which each project served to exclude the types of community participation and empowerment most likely to facilitate health enabling individual and social change. It is framed within the context of Foucault's (1982: 152) injunction to focus on the more subtle manifestations of power, what he calls "the meticulous rituals of power", operating in hidden and subtle places not always immediately evident to the more casual observer.

### *Ekuthuleni Youth Peer Education Project*

The first of these is a youth peer education programme in the peri-urban community of Ekuthuleni, located near Durban, where one in ten 15-24-year-olds were HIV positive (Dept Health, 2003). Funded by a major Australian international funding agency, and administered by a powerful international Christian non-governmental organisation, it sought to limit HIV-transmission through delivering youth-led peer education programmes. The author conducted a detailed case study of the programme, involving interviews and focus groups with a range of community representatives and programme employees (Campbell et al., 2004). The aim of the case study was to identify factors serving to facilitate or hinder the programme's success in increasing youth awareness of the dangers of HIV/AIDS and promoting health-enhancing sexual behaviour change. This was the only formal HIV/AIDS-related programme in the community, and local people were tremendously appreciative of the existence of the programme in principle. As the funders themselves acknowledged, however, the programme was having little impact on youth sexual behavior in practice.

Our evaluation highlighted a number of ways in which the programme fell short of its claims to be community-led and community-owned. The programme proposal was developed by overseas ‘experts’, with little consultation of local people, and a minimal sense of local ‘ownership’ of the project. The programme was run by black South African project workers – whose task was to train local youth to be peer educators. However, whilst project workers came from a similar ethnic background to local Ekuthuleni residents, they were not themselves local people. They lived outside of the community and drove in and out every day to do their work. The local community perception of project workers as ‘outsiders’ and their resentment that local people had not been considered for paid project posts, undermined the development of any sense of local solidarity with programme goals. There was little transfer of educational or organisational skills from the project’s paid workers to local people. Finally, for a variety of complex reasons, the project had little success in building partnerships with public sector health and welfare organisations, or with related NGOs in the region.

As a result, when the project’s international funders withdrew after the three-year period specified on the programme proposal, the programme collapsed, in the absence of any local ownership, skills or support networks to sustain it.

#### *Entabeni ‘barefoot doctors’ AIDS-care project*

The second programme was located in a remote deep rural area of Entabeni in northern KwaZulu-Natal in South Africa. Here 35% of pregnant women are HIV positive (Barron *et al.*, 2007). This project – funded by a major North American AIDS funder – had two goals. Its first goal was to train ‘barefoot’ volunteer community health workers to provide AIDS-care in remote rural community which had limited access to formal health and welfare services. This strategy of ‘shifting’ of tasks from health professionals to trained lay community members is now formal policy in under-served low income settings is now a pillar of

international AIDS policy (WHO, 2008). Its second goal was to build local and regional support networks for the volunteer team, consolidated into a 'partnership' committee that would sustain the volunteers' work over the long term once the project's three-year funded period ended. Furthermore, the project sought to use HIV/AIDS as a springboard to the wider social development of the community.

Contrary to the previous project, members of the Entabeni community were fully involved in the two-year development of the project proposal. Furthermore, the funders were exemplarily non-directive regarding the project's activities. In principle, they were content for the project to evolve in its own organic way, adapting to local needs and conditions, and allowing for time and funding to enable it to build up long-term relationships and support networks. The project has had some significant successes in training a cadre of competent volunteers who have delivered home-nursing and counselling support to large numbers of AIDS-affected households (Campbell et al., 2007).

However, project facilitators are increasingly conscious of the more or less subtle ways in which the funders have imposed their own technical template on the way in which the project conducts and evaluates its work. The timing of the project has been completely at the mercy of the overseas funders' bureaucratic procedures and delays, with no sense of accountability to the beneficiary community. The donor agency has insisted on a 'numbers reached' form of project evaluation, which excludes any recognition of the importance of the community building agenda of the work.

Furthermore, project staff have battled with what they regarded as unrealistic demands for reporting and evaluation, which took no account of the resource and training limitations of project staff. Three overworked project staff spent a significant proportion of their time writing up to seven different funding reports a year, and responding to a range of difficult technical questions (e.g. about levels

of 'knowledge retention' in the community), which they were not qualified to answer, and which bore little resemblance to the project's community-strengthening goals which had been carefully negotiated with local people over a two-year period, and which the funders had accepted in their initial awarding of the grant.

### *Summertown mining industry project*

The third example is drawn from an HIV-prevention project in the gold mining community of Summertown, near Johannesburg (Campbell, 2003). This project was generously funded by a range of major British and North American development and research agencies. Here again, despite its claims to involve grassroots community groups (in particular migrant mineworkers, commercial sex workers and young people) in project management, there were various ways in which community members were excluded from significant participation.

Firstly, the conceptualization of the project was dominated by needs and interests of researchers and funders – who defined project interests and activities in biomedical and behavioural terms, despite ample evidence (from the outset) that social factors would undermine biomedically and behaviourally driven efforts. Secondly, project management was 'top heavy' with medically oriented researchers and scientists, who had no expertise in programme management, health systems development or community liaison, all of which were essential to core project functioning. Finally, as the project gained status in the international donor community, members of highly respected Northern aid and research agencies engaged in distasteful professional turf wars over ownership of research options and findings, with agency staff invariably prioritising their organisations' interests over those of the poor communities they claimed to be assisting.

Within project discourse, the concept of 'community' was manipulated in such a

way that target communities were effectively excluded from meaningful involvement in project decision making. When members of the project's management committee used the term 'community' to denote the managers or agents of the changes the project sought to facilitate, they tended to refer to relatively elite and powerful stakeholder representatives. When they used the term 'community' to refer to targets of change, they tended to refer to the mineworkers, sex workers and township residents. Within project discourse, 'participation' referred to nothing more or less than community volunteers delivering unpaid HIV prevention services. Over time, local township residents became dissatisfied with what they perceived as the project's top-down managerial style. Ironically it was the community's festering anger at being treated as 'objects' rather than 'subjects' of the project's research component that eventually derailed the community strengthening component of the project, leaving project management in the hands of traditional biomedical and behavioural researchers and practitioners who were not familiar with the community development ideals that had informed the project in the first place.

#### *Kumahuswa home nursing project*

My final example involves a home-based care club, set up and managed by an internationally funded NGO, in a small rural community in Zimbabwe. Here again, a so-called community empowerment programme was 'imposed' on the community by an outside agency, there was no local involvement in any aspect of project design, implementation or management, and what was referred to as community 'capacity building' focused on training poor people to provide unpaid welfare services to the community, rather than involving them in programme decision-making or leadership.

This was particularly clearly illustrated in an interview with the Chair of the club. She was an energetic woman, and she and five peers worked enthusiastically to

provide the only formal support available to people with AIDS in the community. They distributed food parcels and blankets to AIDS-affected households, helped them provide nursing care for people dying of AIDS, and met fortnightly to timetable their work and provide one another with support and encouragement. However, despite their dedication and commitment, it was clear that they knew nothing about the context of this work, or the organisation that facilitated it.

*“They no longer bring the blankets and the food parcels, I am not sure why.”*

*“I am not sure who initiated this group.”*

*“We (the five women) don’t network with anyone besides each other.”*

*“We have run out of gloves and we need a refresher course.”*

*“I am not sure of the future plans of this group because I am not part of the management.”* (Anna K, cited in Nhamo and Campbell, 2008)

## **Discussion**

In debates about political will, organisations implementing programmes in Sub-Saharan Africa usually assume that it is others that must change – others such as ‘problematic’ African leaders, or ‘promiscuous’ community members. It is the argument of this chapter that as members of external organisations (in our roles as academics and development practitioners, for example) we are equally complicit in development failure in more subtle ways. There is an urgent need for us to look at how our *own* actions and practices contribute to disappointing programme results.

The case studies outlined above seek to highlight ways in which the practices of development agencies may often run directly counter to processes of empowerment and capacity building that are necessary preconditions for more effective HIV-prevention and AIDS-care. Too often discourses of ‘participation’ and ‘community mobilisation’ are used as a smokescreen for programmes in which local people are used to provide unpaid welfare services according to an

externally imposed agenda, but quite systematically excluded from any meaningful involvement of the type that would facilitate health-improving social psychological changes.

Here it needs to be emphasised that facilitating genuine and effective community participation is not easy. Furthermore proper community 'buy-in' and grassroots engagement in health programmes is only one of several necessary preconditions for success. Elsewhere, for example, we have argued that marginalised communities are unable to solve major health problems without strong support from outside agencies (Nair and Campbell, 2008). However, in the absence of meaningful involvement of communities, little can be done to help the most HIV/AIDS-vulnerable groupings. Studies repeatedly cite proper community participation as vital for effective prevention, accessing of services, treatment and care.

Discussions of the complexities of implementing effective community engagement, and of the failure of generations of development programmes to bring about sustainable reductions in poverty and ill-health, tend to generate both pessimistic and optimistic conclusions. These depend on the ways in which different commentators conceptualise power. Those who view power as a monolithic entity, possessed and wielded by the strong against the weak and powerless, tend to conclude pessimistically. Such commentators suggest that the failure of so-called 'development' programmes – funded by rich western countries and implemented in poor countries – is part and parcel of the on-going and systematic perpetuation of global inequalities.

Prominent amongst this group is Escobar (1995: 39) who argues that the history of the relationships between rich and poor countries is structured in such a way that "it has created a space in which only certain things can be said or even imagined". In short it enables only the saying and imagining of forms of 'community participation' that systematically exclude the possibility of effective

community involvement, and of the development of leadership capacity amongst the world's poor and dispossessed. These involve nothing more or less than "the collapse of social emancipation into social regulation". (Escobar, 2004: 213; Cooke and Kothari, 2001). In a similar vein Kitching (1989: 195) comments that: "Development is an awful process. It varies only ..... in its awfulness."

More optimistic commentators shy away from what they argue is a simplistic and one-dimensional account of power as a force held by some groups and not others, and used by the former to retain their unambiguous hold on power over the latter. They reject what they identify as the implicit dualism between all-powerful international development agencies and powerless impoverished Africans. Citing Foucault, they argue that power can be productive as well as repressive, and that wherever power is wielded, there lies the possibility of resistance. Within this vein, Lewis and Mosse (2006: 10) argue that "reality is messy ... [and that] encounters between developers and people tend to be much more complex and nuanced than meets the eye".

What might this mean in the context of the case studies outlined above?

Frederick Douglass (cited in Seedat, 2001) argues that 'power is never conceded without a demand', and that elite groups seldom hand over power without vociferous demands from the excluded. Perhaps it is the case that even flawed projects of this nature give members of marginalized groups a glimpse of the possibility of playing more active and empowered roles in their social and public lives. This might include women, young people, rural people and the poor – the groups most disproportionately affected by HIV/AIDS in Africa. Such glimpses might even be important though veiled milestones on the long road of building the skills, confidence, networks and platforms for making the 'demands' that Bulhan speaks of in increasingly assertive and effective ways over time.

This chapter has focused on the technologies of participation and capacity building in the context of HIV/AIDS management in four economically deprived



southern African settings. Much remains to be learned about the way in which various elements of this paper's analysis would be relevant to HIV/AIDS work with socially excluded groups in other low and high income contexts. Furthermore, the focus of this particular chapter has been HIV-prevention and AIDS-care, with none of the four case study communities having access to antiretroviral drug treatment at the time of writing. However, preliminary studies suggest that wherever possible, prevention, treatment and care need to go hand in hand for optimal outcomes (Achmat and Simcock, 2007). Furthermore it is very likely that meaningful community participation will be an important influence on treatment success in marginalised settings, given that treatment access and adherence is heavily affected by community-level factors such as AIDS-stigma, and the social and cultural appropriateness of services (Campbell *et al.*, 2005; Coetzee *et al.*, 2004).

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