

Strengthening community responses to AIDS: possibilities and challenges¹

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Pathways between social capital and health

At the AIDS2031 Meeting in Salzburg, I will discuss the case study outlined in this chapter with specific reference to the following points:

- What does this case study tell us about the types of social capital that enable or limit the ability of poor people, especially women, to respond effectively to HIV/AIDS?
- What is the role of social capital in building 'AIDS competent communities'?
- What is the difference between 'externally imposed interventions' and 'interventions that facilitate local community responses', and why is this such an important distinction?
- How can the concept of the 'AIDS-competent community' – with bonding and bridging social capital at its core – best be used as a tool for programme design and evaluation?

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Introduction

Many AIDS programmes in sub-Saharan Africa have had disappointing results (Gregson *et al.* 2007), with HIV rates continuing to rise, stigma remaining stubbornly resistant to change, and access and adherence to treatment and support remaining inconsistent. Other interventions have worked well in carefully controlled research conditions, but these have been difficult to scale-up in less highly monitored 'real world' settings (Binswanger, 2000; Chopra & Ford, 2005). One key reason for the less than optimal outcome of many programmes is that they fail to resonate with the worldviews and perceived needs and interests of their target groupings, or to take adequate account of the complex social relations into which programmes are inserted (Pfeiffer, 2003; Gruber & Caffrey, 2005). Too many programmes are imposed on communities in 'top down' ways by outside experts. In such settings, target communities are seen as passive recipients of prevention, care and treatment services rather than active participants working in partnership with health professionals to improve their health (Campbell, 2003).

Community involvement is increasingly being cited as a vital precondition for effective HIV/AIDS management. It is said to play an important role in enabling health-related behaviours and reducing HIV-transmission (van Wyk *et al.* 2006), and in the reduction of stigma (Poku & Sandkjaer, 2007). It is also vital for facilitating timely and appropriate accessing of health and welfare services where these exist (Hadley & Maher, 2001; Segall, 2003; Bak, 2004), and for supporting optimal treatment adherence (Coetzee *et al.* 2004). International and national policy repeatedly advocates the need for community participation in HIV/AIDS work (UNGASS, 2001; South African Government, 2007). Yet much remains to be learned about how best to facilitate such involvement (Campbell & Foulis, 2004).

There are two reasons for our particular interest in community involvement. The first is a practical one. With the overall scarcity of health workers, exacerbated by the so-called 'brain drain' of African health professionals,

volunteers are earmarked for an increased role in HIV/AIDS management, with a growing number of projects relying on grassroots community members to provide HIV-prevention and AIDS-care services in their communities (Ogden *et al.* 2006; van Damme *et al.* 2006; Schneider *et al.* 2008). The second reason for the importance of community involvement – which forms the context of this chapter – is a social psychological one. Community participation provides a vital opportunity for the development of community-level AIDS competence - the ability of communities to respond as effectively as possible to the challenges of HIV/AIDS.

In this chapter we discuss community participation in the light of our three year involvement in a community-led HIV/AIDS management programme in rural KwaZulu-Natal (Campbell *et al.* 2007a; Campbell *et al.* 2008e). Entabeni is located some distance from the nearest town. Geographical isolation, poor roads, high costs of transport and lack of confidence limit peoples' access to formal health and welfare services. Polygamy is common, and women have limited power to protect their sexual health, particularly within marital relationships where their husbands have paid *lobola* (bride-wealth) for them. Levels of HIV/AIDS are 34.6% amongst pregnant women, and AIDS deaths, especially of young people, are a common occurrence (Barron *et al.*, 2007). Despite this, there continue to be high levels of AIDS denial and stigma (Campbell *et al.* 2007b).

This chapter's authors constitute the 'Community Responses to AIDS' team at the Centre for HIV/AIDS Networking (HIVAN) at the University of KwaZulu-Natal. They were invited to conduct research in Entabeni, to identify the most effective local community responses to HIV/AIDS, and to work with local people to see how these could be supported and developed. The research highlighted the existence of a strong, united team of volunteer health workers – nearly all women, though with a male leader – who were the main source of assistance to families and households with members dying of HIV/AIDS (Maimane *et al.* 2004). The volunteers had been mobilised and trained through the uncoordinated and often temporary inputs of religious missionaries, patchy government interventions and NGOs. Most worked for

no pay, and with little or no training, walking long distances on foot up steep hills, often in searing heat, to AIDS-affected households.

Their work was often gruelling, fetching wood and water, cooking, cleaning sick and dying patients, and supervising the transport of people in wheelbarrows to distant roads to seek transport to the hospital 30km away. Their efforts were often constrained by their lack of literacy, of formal HIV/AIDS training, and of any form of payment or even stipend to cover their expenses. Their commitment persisted despite lack of supportive health and welfare systems, with little recognition from local leaders or the church (the most established community network), dealing with the most challenging of health problems in a climate of hunger, poverty and often hopelessness (Campbell *et al.* 2008e).

Over the course of one year, HIVAN conducted detailed research in Entabeni. In the next year, the team reported their findings to key community groupings, working with community members to formulate a three-year project proposal (Campbell *et al.* 2008f). HIVAN was able to raise money to fund this project. It sought to strengthen local community responses to HIV/AIDS through enhancing volunteer skills and building support networks for their work both within and outside of the community. Before discussing the project's activities, progress and challenges, we will outline the concept of an 'AIDS competent community' which informed our work in Entabeni.

Our discussion below showcases many of the challenges facing the project. At the outset we emphasise that we have no doubt that meaningful community participation is a vital precondition for optimally effective programmes. Furthermore, our experience suggests that there is tremendous will, talent and energy, particularly amongst grassroots women, to make a significant contribution to the AIDS struggle. Starting from these assumptions, this chapter aims to generate 'critical thinking' about the determinants of effective participation – to generate debate and dialogue about the challenges involved, and how they might best be tackled.

Conceptualising the ‘AIDS Competent Community’

Current social psychological approaches to HIV/AIDS often draw heavily on social cognition models of behaviour, which focus on individual-level determinants of health-related behaviours – such as individual attitudes, perceived self-efficacy, perceived social norms and motivation to comply with these. However, the likelihood that people will engage in health-enhancing behaviours depends not only on individual-level factors, but also on the extent to which they live in social environments which enable and support health-enhancing behaviours (Campbell, 2003, Tawil *et al.*, 1995). Against this background, we seek to develop understandings of the contexts in which HIV/AIDS interventions are located, and the extent to which they enable or limit the likelihood that community members will respond effectively to the challenges of HIV/AIDS prevention, care and treatment.

People are most likely to act in ways that enhance their health and well-being when they live in what we call ‘AIDS competent community contexts’ (Campbell *et al.* 2007a; Campbell & Nhamo, 2008). We define an AIDS-competent community as one where community members work collaboratively to support each another in achieving: sexual behaviour change; the reduction of stigma (often deterring people from accessing prevention and care services); support for people living with AIDS and their carers; co-operation with volunteers and organisations seeking to tackle HIV-prevention and AIDS-care; and effective accessing of existing health services and welfare grants. Underlying these behaviour changes are five key psychosocial characteristics of an AIDS competent community.

Knowledge and skills

In an AIDS competent community, residents have knowledge about how to prevent HIV, basic skills for nursing people with HIV/AIDS, and an understanding of how to access the health and welfare system. However, knowledge and skills are only the first step. At this stage of the epidemic, many people have good factual information about HIV/AIDS. The problem is that this information is often presented in such a way that people cannot ‘*translate*’ it into action plans in their own lives.

Social spaces for dialogue and critical thinking:

What people often lack is not so much information as safe 'social spaces' in which they might, through discussion, start to collectively examine ways in which they might use this information in their own lives, renegotiating individual and social norms that undermine their own and others' health and well-being. Low-Beer and Stoneburner (2004) emphasise the value of informal interactions between community members. These provide contexts in which people feel confident to engage in dialogue and debate about the highly stigmatised topic of HIV/AIDS, gradually taking ownership of alien medical facts, airing any doubts or confusions they may have about them, and discussing ways in which the new information conflicts with their existing worldviews and practices.

Over time, people gradually process AIDS information in ways that do not conflict too starkly with their key pre-existing life goals or values – and in ways that they can realistically apply in their own daily lives. This might involve taking precautions to protect their own sexual health, offering appropriate care and support to AIDS-affected people, and developing less stigmatising ways of talking about the problem. Such social spaces might include for example, conversations between neighbours, families or peers – in their living rooms, on buses, at school, in the street – in any place where people meet on a day-to-day basis and co-construct the social knowledge that shapes their worldviews and behaviours (Farr & Moscovici, 1984).

Three concepts influence our understandings of social spaces. The first is Freire's (1970; 1973) concept of *critical thinking*. 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 about ways in which they might – individually and collectively – resist such obstacles. The second is Habermas' (1992) idealised concept of the *public sphere*, which characterises the optimal conditions for effective critical thinking and dialogue. Participants in debate meet as peers, engaging in discussion in conditions of equality; ideas are evaluated in terms

of the sense that they make to participants, rather than in terms of the extent to which they support the status quo (Jovchelovitch, 2001). The third concept is that of *social identity*. People are most likely to change their attitudes and behaviours when they see that liked and trusted peers are changing theirs (Campbell, 2003).

Ownership/responsibility

Effective social spaces provide contexts where community members can develop a sense of ownership of HIV/AIDS and a sense of responsibility for tackling it. In conditions of denial and stigma, people may fail to acknowledge its existence altogether. However, even when they do so, they might respond with a sense of helplessness and fatalism, passively waiting for government or NGOs to come and tackle the problem – and distancing themselves from any responsibility, rather than acknowledging that they too have a role to play (Barnett & Whiteside, 2006).

Solidarity and common purpose ('bonding' social capital):

Ideally such social spaces provide a trusting and safe environment where people can reach collective decisions to behave in more health-enhancing ways, and develop a sense of solidarity and common purpose around implementing these decisions. This sense of solidarity and common purpose amongst local community members constitutes the fourth criterion for an AIDS-competent community. Cornish & Ghosh (2007) point out that geographical communities – such as Entabeni – often consist of groups who have very little in common, whose relationships are characterised by varying degrees of co-operation and conflict, and whose lives are centred around the pursuit of competing interests (e.g. leaders/subjects, adults/youth, men/women, employed/unemployed). An AIDS competent community is one where local people are able to reach out to one another, in spite of their differences, to create a sense of common purpose to tackle the impact of HIV/AIDS on the community, both through working to prevent transmission, and through offering optimal support and care to AIDS-affected people.

Such 'strategic alliances' (Spivak, 1988) form the context in which people work together to formulate strategies for how they can tackle the problem – both individually, and through existing social networks. At an individual level people can contribute to the fight against AIDS through efforts such as praying for people with AIDS and their carers, helping affected families with daily tasks such as housework, showing kindness to people living with AIDS and so on. At the community level, there is much that existing social groups e.g. youth groups, womens groups and church groups can do to support AIDS patients and carers, and to provide safe and supportive group contexts in which people can disseminate and debate how best to apply HIV/AIDS related information in their own lives.

Bridging social capital

The fifth and final criterion for an AIDS competent community is the awareness of, and the ability to forge links with, external organisations (e.g. in public sector or civil society) capable of supporting community members in tackling HIV/AIDS. Members of marginalised social groupings seldom have the power to tackle serious social problems without the support of outside agencies with the political and economic clout to assist them in meeting their goals. Bridging social capital is a key precondition for effective community responses to AIDS (Evans, 1996; Woolcock, 1998).

The Entabeni Project

The aim of the Entabeni Project was to promote these five criteria for HIV/AIDS competence through two strategies. Firstly, to strengthen the ability of the existing volunteer team to lead the local response to HIV/AIDS through facilitating their access to the skills they said they needed in three areas; i) home-based nursing and counselling skills to improve their care work; ii) peer education and training skills to disseminate their knowledge to the community and generate social spaces; and iii) networking skills to enable them to advise AIDS-affected families on how to access health and welfare services and grants.

The second strategy was to strengthen support structures for the volunteers both within and outside of the community. In our baseline research, volunteers said the most valuable sources of within-community support be local leadership and the church, both of whom had traditionally kept of a distance from the volunteers. They also spoke of the need to get more young people and men involved in various HIV/AIDS related activities. Men were identified as a key group to mobilise because of a community-wide perception that many refused to recognise the dangers of HIV/AIDS or to agree to use condoms with their wives, even when they had multiple partners.

The project also sought to link volunteers with potential partners in government health and welfare departments and NGOs. These would aim to make local health and welfare services more responsive to community needs, and support volunteers in various ways. Initially several potential outside partners expressed an interest in being part of a 'community strengthening' project of this nature, saying they had previously lacked the community contacts and access to do this.

The volunteers were keen and willing to take on leadership of the project, but said they could not do so without substantial external support. Against this background, the Entabeni AIDS Partnership was formally constituted, consisting of a three-way partnership: (i) representatives of the local community, including local leaders and volunteers; (ii) external partners from the public sector (health, welfare, regional municipality) and two small NGOs; and (iii) HIVAN in a co-ordination role. HIVAN raised funding for two full-time staff (the 2nd and 3rd authors of this paper), who served as the project's 'External Change Agents'. Their role was one of co-ordination – to convene regular three-monthly meetings of local and external partners, to monitor the implementation of decisions made at partnership meetings, and to work to link project participants with external sources of support in areas such as training, fund-raising and development of management skills.

Building volunteer skills

The project's goal of building AIDS-related skills in the volunteer group was relatively easy to achieve. The volunteers were already a mobilised and united group. They participated enthusiastically in various training programmes facilitated by NGOs that HIVAN linked them to. Once they were trained, they worked hard to train other lay women in these skills. A core group of predominantly female volunteers worked tirelessly to deliver assistance to AIDS-affected households, lead peer education programmes, organise local HIV/AIDS awareness events, staff the AIDS outreach centre set up by the project, advise people on how to access health and welfare grants and services, and so on. However the task of building support networks for the volunteers – both within the community and with outside partners – was beset with challenges, discussed below.

Building bridges between volunteers and external partners

The project's three-year attempts to build sustainable bridging relationships between community representatives and external support agencies (the 'external partners') proved almost impossible (Nair & Campbell, 2008). At the outset, various public sector health agencies expressed interest in being part of the project, but the challenges of turning intentions into action were immense. The first of these was the nearest government hospital. There were many obstacles to community uptake of hospital services – poor roads, unaffordable transport, long queues at the hospital and a lack of skills and confidence to make optimal use of services. The hospital superintendent expressed his appreciation of the value of building partnerships with remote communities to improve service access and treatment adherence. However the hospital faced resource constraints, even in providing traditional care, let alone engaging in complex unstructured activities such as community liaison. Senior hospital staff were too busy to attend project meetings, and sent junior representatives. Juniors lacked the authority to make decisions on behalf of the hospital, so their participation in meetings was tokenistic, seldom leading to concrete action.

The second potential external partner was the local Primary Healthcare Clinic. She was specifically charged with supporting local volunteers. However she lacked personal motivation to engage with the project. She had no training in community liaison, and few channels or skills to communicate with volunteers, or with her own supervisor. At her request, impoverished health volunteers battled to find pens and paper to write monthly reports for her about their activities. She summarised their reports for her superior. However, she didn't receive any feedback from her supervisor, nor did she give any feedback to the volunteers, or advise them on how to deal with the problems described in reports.

There was a District AIDS Office in the town nearest Entabeni. This office paid the volunteer leader a small stipend. HIVAN co-ordinators encouraged him to visit the office to discuss problems arising in his team coordination task. His visit to the agency was greeted with hostile incredulity. The office worker was affronted that a humble community member had visited her office without invitation. She refused to engage in any discussion – saying he was wasting Health Department money by being away from the community where he was paid to work, and that she would ensure his stipend was reduced to compensate for the day he had 'wasted' away from the community.

The regional municipality office is specifically charged to assist communities with social development projects. A senior official was keen to participate in the project. Participation in our project fitted into his job description, and he hoped our project style of partnering could serve as a 'best practice' model for his organisation. However it soon became clear he didn't have the time to participate or answer our calls. His secretary said he was 'drowning in projects', on a shoestring budget in a huge catchment area overwhelmed by poverty and HIV/AIDS. He was also limited by his accountability to a pool of competitive local councillors. When he enthusiastically explained the potential of the Entabeni Partnership as a pilot project for the region, they forbade him from offering special assistance to a single community, saying that anything he did for one community, should be done for all.

Over three years, the project's sustained efforts to build long-term partnerships with public sector bodies specifically charged with facilitating greater community involvement in AIDS and health in Entabeni were disappointing.

The most promising partners have been two NGO's – small, under-funded and run by deeply committed individuals. The first is the Entabeni Development Committee, run by a Norwegian woman, with no formal institutional links. Driven by religious convictions, she has lived in Entabeni for several years – working closely with local people to set up a crèche, community gardens and craft projects. When HIVAN first entered the community, she had already put a lot of work into training local people to build and staff a small AIDS hospice. She has been an important participant in the project, playing a key role in supporting and advising carers, assisting with transport and catering at project events and so forth. Her involvement is characterised by her strong commitment to proper community ownership of all activities. She is determined never to control or take credit for the group's achievements, and is well-liked and trusted by local project participants.

The second NGO is the regional branch of national counselling charity run by a retired British business woman, who raises her own funds. This NGO has played a key role in various forms of home-based care and peer education training, both of health volunteers and of schoolchildren. It has also been involved in setting up, running, and paying a part-time administrator to manage a local Entabeni AIDS Outreach Centre, in vacant buildings donated to the project by a local leader.

These two organisations have played a key role in the project, never missing a meeting, always being on hand with well-informed advice and networks, and shaping their activities in response to needs and problems articulated by the project and by community members.

Building within-community support networks for the volunteers

Historically the health volunteers had operated with little local support, in a context of AIDS stigma and denial. There was little recognition of their work, and little practical support for their efforts by local leaders or grassroots residents. A key goal of the Project was to create social spaces where people could talk about AIDS in a constructive and positive way – with particular efforts to engage the church, local leaders, young people and men.

The church is the biggest formal community network, and a significant potential resource for sharing information, and offering support and prayer to the sick. However whilst many individual church leaders and members were nursing AIDS-affected relatives, this was done in private, seldom acknowledged in formal church meetings. The few references to AIDS tended to be judgemental, e.g. ‘God’s punishment for immoral behaviour’ (Campbell *et al.* 2007a). Many churches discouraged condoms, ignoring the fact that many members engaged in sexual activities outside monogamous marriages. The project had some success in involving church leaders in its training and awareness activities. In independent project evaluations Entabeni residents pointed to increased openness and opportunities for discussion of AIDS in local churches as one of the project’s positive achievements (Mqadi, 2007; Campbell *et al.* 2008a).

Prior to the project’s inception, health volunteers repeatedly complained their efforts were undermined by the lack of support from local leaders (Entabeni was governed by a traditional leader, who delegated ward-level power to lower-level ward leaders). A key project goal was to build this support. The project had little success in mobilising ward leaders – many of whom continued to ignore the existence of the volunteers, and to avoid any participation in AIDS activities. Very few attended the project’s AIDS and leadership training workshops.

The project had more success in getting support from the community’s traditional leader. As the supreme community gatekeeper, it could not have operated without his permission. He spoke openly about AIDS at community

meetings, and participated in the Project's formal occasions, including the opening of the Outreach Centre, and the graduation ceremonies held after training courses. However, his style was often at odds with project goals (Campbell & Gibbs, 2008b). Thus for example he often used speeches at project events as a forum for celebrating his own masculinity, frequently referring to his 6 wives and 5 girlfriends. He also used speeches to express his view that polygamy was not related to HIV-transmission, since wives and girlfriends should be virtuous and faithful. Furthermore, in an indirect way, his authoritarian style of governance, and his conservative attitudes to women and youth, were undermining of the project's 'empowerment via participation' agenda. They created a social environment that stifled the creativity, initiative and 'thinking out of the box' that are hall marks of successful social development (people enthusiastically collaborating to develop new ways of getting by and getting ahead). It also hampered the development of the confidence and empowerment central to the project's ideal of AIDS competence outlined above.

Another key goal was to get young people more involved in local AIDS work, as a springboard for their wider social development – through skills-building and leadership training. In the project's baseline research young people expressed a strong desire for opportunities to participate in community activities, seeing this as a stepping stone to future self and career development (Campbell *et al.* 2008c). Despite this, the project had little success in recruiting or retaining youth. In later research into this problem (Campbell *et al.*, 2008b) youth raised various reasons for their poor participation in the Project. They said local adults were reluctant to recognise the value of young peoples' inputs, or to respect them as equals in Project structures. This resulted in tokenistic youth representation on committees, which further discouraged their participation. They also expressed bitterness about the way the concept of volunteering was 'abused' to get youth to provide unpaid labour for local projects. Yet when local paid work opportunities arose they always taken by adults, and youth were excluded.

The project's final challenge was to target men for AIDS training and awareness, and to involve men in project activities. Very small numbers of men became involved in the project, those that did tended to be unmarried youth, church leaders, or the few men who dominated the small number of paid jobs associated with the project. Nearly all the volunteer work has been done by women. Project research has pointed to various reasons for this. Given that men have greater access to paid work than women, and the ideology of the male breadwinner, men are unwilling to work without payment, seeing this as pointless and as demeaning to their status. Many men regard issues relating to health and caring as 'women's work'. Furthermore, for many men, taking risks and having multiple partners, is part of their socially constructed masculinity – the messages of AIDS prevention, which urge caution and partner reduction don't appeal to many men (Campbell, 1997). Finally in a remote rural community, the most motivated and able men are either in full time work, without time for Project participation, or are away as migrant workers. Unoccupied men were described as the least skilled and employable, and thus the least confident and motivated for involvement in projects.

Volunteer challenges

As discussed above, members of the volunteer team have worked tirelessly to enhance their nursing and counselling support for AIDS-affected families. The training provided by the project has increased their confidence, and they have engaged in numerous activities – running peer education and home-nursing courses for local people, helping set up and run the project's Outreach Centre and organise several high profile AIDS-awareness events (Campbell *et al.*, 2008d). Furthermore a core group of volunteer representatives have represented the project at regular meetings with external partners and at numerous conferences and policy workshops in the region.

However, over 3 years, the project's failure to secure a sustainable long-term stipend for most volunteers has meant that the turnover of volunteers is high – with women often attending the training and participating energetically in supporting households, but eventually dropping out. The project has retained

a small but solid core of older religious women whose husbands support them. But the team depends heavily on the input of younger women, who are more difficult to retain since many have children to support. For several years volunteers have engaged in a yo-yo process of hope and despair in the face of a string of ambiguous and unmet promises by various government agencies, suggesting the volunteers will eventually receive small stipends. However the Entabeni volunteers have never quite managed to qualify for the conditions attached to these. Their failure to materialise has exacerbated the drop-out rate.

At various stages, HIVAN has been able to raise donor funds for small temporary stipends to cover volunteers' expenses, but these and not the sustainable and institutionalised public sector recognition and support that younger volunteers hope for. Furthermore, the Project has not had the capacity to monitor the performance of volunteers receiving these. This has led to bitterness and despondency amongst more hard-working volunteers – when they see some of their peers receiving equal stipends for doing much less work.

Other tensions have also arisen in the volunteer group. Despite the project's very explicitly defined 'women's empowerment' focus, and although nearly all the volunteer workers are women, as stated above, the team's handful of paid leadership positions have been dominated by men. In formal Project meetings these men pay lip service to delegating and sharing responsibility with women volunteers, however in reality they have failed to do this. They have also sometimes responded in ways that women volunteers found aggressive and intimidating on the few occasions they timidly attempted to challenge their male leaders to be more accountable to them.

Conclusion

Our starting assumption has been that community participation can greatly enhance the AIDS competence in marginalised communities where HIV is high and formal support and services are low. We have presented our longitudinal case study of a project that sought to promote such participation –

through building HIV/AIDS-related skills and knowledge, facilitating opportunities ('social spaces') for dialogue about HIV/AIDS, promoting solidarity and common purpose across diverse community groupings, an enhanced sense of ownership and responsibility for tackling the problem, and supportive bridging relationships with outside agencies.

What has the Entabeni Project achieved over three years, framed in terms of our five-factor concept of the 'AIDS competent community'? Whilst no formal outcome evaluation has been conducted, our personal involvement in the community as well as two separate process evaluation exercises (Mqadi, 2007; Campbell et al. 2008a) suggests it has been very successful in building the skills of a core group of volunteers to provide nursing care and counselling to AIDS-affected households, skills that have been used in offering a vital and valued enhanced nursing and counselling support service to many AIDS-affected households. The Project has also been successful in increasing the social spaces available to local people (particularly young people and church members) to talk openly about AIDS, and in building the confidence of volunteers to tackle the problem. It has mobilised the open support of the community's traditional leader, though in the ambiguous way outlined above.

However the project has been less successful in building widespread support and solidarity amongst the wider community beyond the volunteers, and it has been unsuccessful in mobilising men and ward local leaders. Whilst many youth have attended Project training courses at various stages, the drop-out rate has been high, and the Project has had disappointing results in retaining the involvement of youth who completed these courses.

Finally, whilst the project has been successful in mobilising the involvement of extremely effective NGOs, these have been small and under-funded agencies. Whilst these have the advantage of having the flexibility and will to be responsive to community needs as they arise, they are not necessarily long-term or sustainable supports. Such links would have to be continually renewed as different NGOs rise and fall with changing donor priorities. Efforts

to build long-term institutionalised partnerships with formal public sector agencies have also had disappointing outcomes.

What are the lessons for those seeking to promote community participation in AIDS programmes in under-served rural areas? Our experience suggests that there is a pool of remarkable energy and talent amongst rural women to participate in community health projects. However their efforts and motivation are severely constrained by lack of any formal recognition of their value and their hard work. Furthermore, the majority of volunteers in Entabeni lack the educational levels, and formal institutional links, that would qualify them for government stipends. Until some way of tackling this problem is developed, their potentially major contribution to HIV/AIDS management will be undermined.

Gaining the support and participation of local leaders, youth and men in projects is also dramatically undermined – much work remains to be done in developing policies and strategies for engaging them. In the conservative rural setting of Entabeni, many traditional leaders rely heavily on their self-styled roles as ‘guardians of tradition’ to justify their hold on power (Campbell and Gibbs, 2008b). A key aspect of the way in which they interpret ‘tradition’ involves the power of adult men over women and youth, and a conservative interpretation of masculinity including the right of men to have multiple wives/sexual partners. These so-called ‘traditional’ norms were at variance with the ‘empowerment via participation’ agenda of the Entabeni Project, which sought to strengthen the role of youth and women in leadership of community projects, and also to get men to take greater responsibility for their role in the transmission of HIV/AIDS. Our experiences highlight the irony that many of the most powerful members of the Entabeni community have a vested interest in preserving the very social relations that facilitate HIV-transmission and undermine the well-being of people with AIDS.

The efforts of the Entabeni volunteers are actively undermined by lack of appropriate capacity, mandated to support them. There is an urgent need for the government to prioritise the development of community outreach and

support skills amongst relevant agencies in the health and welfare sectors, and to acknowledge and institutionalise grassroots community members' key role in tackling HIV/AIDS. Elsewhere (Campbell and Gibbs, 2008a) we have argued that dominant representations of the HIV/AIDS struggle in the public sphere in South Africa depict it in an overwhelmingly top-down way as the responsibility of senior political leaders and health experts. There is virtually no recognition of the fact that the major burden of HIV/AIDS management in poor communities is already carried by unpaid women, or of the fact that communities could play a vital role in ensuring optimally effective outcomes for prevention, care and treatment efforts.

Once again we must emphasise that whilst this chapter has focused heavily on the challenges that faced the Entabeni Project, this by no means indicates any doubts on our part about the vital role that community participation has to play in HIV/AIDS management in South Africa, or about the need for redoubled efforts to think of ways in which the challenges outlined can best be negotiated. Our case study is presented to promote critical thinking about the obstacles that stand in the way of effective participation. Many of these obstacles are rooted in wider socio-economic inequalities that lie beyond the reach of small community programmes. However, as Bulhan (cited in Seedat, 2001) says, 'power is never conceded without a demand'. Elites (such as men, or adults, or leaders, or public sector employees) seldom voluntarily give up power without vociferous demands from the oppressed (be they women or youth or stigmatised people with AIDS). Aside from their important value in providing vital health and welfare support to desperately under-served groups, small-scale efforts such as the Entabeni Project have a key role to play in the long-term struggle of equipping such groups to make these demands in increasingly confident and forceful ways.

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