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Building 'HIV competent communities' in resource poor settings: creating contexts that enable effective community mobilization.

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Abstract

Whilst community empowerment is a pillar of HIV/AIDS policy, less attention is given to creating contexts that support communities in putting new skills and capacities into action. Our conceptualisation of 'community HIV/AIDS competence' addresses this challenge. We discuss two very different case studies (in South Africa and Kenya) which sought to facilitate local HIV/AIDS competence through (i) empowering marginalised groups to respond more effectively to HIV/AIDS, (ii) building local support for such efforts and (iii) facilitating supportive partnerships with donors, policy-makers, NGOs and public sector agencies outside of the community. We pay particular attention to the local-global relationships that provide the most enabling context for the strengthening of local community responses to HIV/AIDS.

Keywords

Community mobilisation, health-enabling contexts, HIV/AIDS competence, social capital, partnerships, donors, local-global.

Introduction

Community participation is widely accepted as a vital component of effective HIV/AIDS management, especially in many of the marginalised settings in which HIV/AIDS flourishes. However, successful community mobilisation is extraordinarily difficult to bring about. Historically heavy emphasis has been placed on the challenge of building community skills and capacity in the areas of HIV prevention, care, treatment and impact mitigation. There has been too little parallel attention to the challenges of building social environments that enable and support effective community empowerment. This is particularly the case in relation to ensuring that communities are supported by enabling partnerships with the public sector, NGOs and donors, and by social policies that institutionalise the need for community engagement.

We present our model of 'community HIV/AIDS competence' as a frame for greater context-friendly analysis and action, illustrating it with two very different rural African case studies. Both of these externally funded programmes sought to support the development of community HIV/AIDS competence (in relation to the provision home-based care to the sick and dying, and the support of HIV-affected children respectively) through empowering local communities with HIV/AIDS-related capacity and skills and building social environments that supported their effective implementation. We explore the obstacles and opportunities each project faced along the way, linking our argument to wider debates about the extent to which externally designed and funded projects open up or close down opportunities for agency by marginalised communities in resource-poor settings.

Three generations of approaches to HIV/AIDS management

Community mobilisation has emerged as part of the 'third generation' of approaches to HIV/AIDS management (Campbell & Cornish, 2010). The first generation, which dominated in early prevention efforts, focused on providing individuals with information about health risks, on the assumption that people

engaged in unprotected sex due to lack of knowledge about HIV/AIDS, the fact that they themselves might be at risk, and how to prevent infection. This second generation of approaches targeted the peer group rather than the individual, on the assumption that peer norms were the most significant determinant of health-related behaviours, related both to prevention and care. As the emphasis in the response shifted from a primary emphasis on prevention and care, to include greater attention to treatment and impact mitigation, a third generation of approaches targeted not only the individual and peer groups, but also the community, in order to create local community contexts that were most likely to support effective local responses to HIV/AIDS.

Such approaches focus on building HIV-competent community contexts. Because public health interventions most commonly target their efforts at geographically defined communities, we use a place-based definition of community in our work. We characterise HIV-competent communities in terms of the psycho-social features of a community in which local people are most likely to collaborate with one another, and outside support agencies, to develop effective local responses to the challenges of prevention, care, treatment and impact mitigation (Campbell, Nair, & Maimane, 2007; Nhamo, Campbell, & Gregson, 2010). The concept of community HIV/AIDS competence serves as a framework for the design, implementation and evaluation of community-led approaches to HIV/AIDS seeking to facilitate safer sexual behaviour, stigma reduction, service access, treatment adherence and impact mitigation.

Community involvement is a pillar of international HIV/AIDS intervention and policy rhetoric. It is considered vital for three reasons (Campbell & Cornish, 2010). The first relates to the need to 'translate' externally conceived HIV/AIDS management approaches into locally and culturally appropriate discourses and practices in real world settings. Peoples' experiences of, and responses to, HIV/AIDS may be embedded in local worldviews and survival strategies that have a poor fit with the biomedical and behavioural frames of reference that tend to dominate globally conceived programmes. Secondly,

community mobilisation is deemed necessary for building local capacity to 'sustain' externally funded programmes once their funded period is over. The participation of local people in HIV/AIDS management and impact mitigation efforts is also central to the 'task shifting' agenda that is increasingly emphasised in global responses to health (WHO, 2008), with its emphasis on the need to strengthen health systems in affected settings.

The third reason for community participation, most relevant to this chapter, relates to the social psychology of health-related behaviour change. People are most likely to behave in ways that optimise effective HIV/AIDS management if they live in social environments that enable and support health-enhancing behaviour (Tawil, Annette, & O'Reilly, 1995). To date, efforts to mobilise communities tend to be pursued in an ad hoc way, in the absence of clear underlying models of the psycho-social processes that mediate between participation and health. In our work, we draw on the 'social psychology of participation' (Campbell & Jovchelovitch, 2000), to conceptualise the social environments in which people are most likely to work together to facilitate effective community responses to HIV/AIDS.

Promoting HIV/AIDS competent communities

Opportunities for positive social participation are core to creating HIV/AIDS competence. There is growing evidence for the direct and indirect health-enhancing impacts of positive local participation (in informal or formal networks related to friendship, leisure, spiritual faith, community activism and so on, as well as health-oriented projects) (Gregson, 2010). Directly, social participation can lead to benefits such as increased access to information about health problems and how best to avoid or respond to them, better access to practical, emotional and material support for the ill and the confidence to cope with or challenge social stigma. Indirectly social participation may be associated with various forms of empowerment (e.g. increased income generation opportunities, enhanced social recognition, opportunities for community activism) which may also increase opportunities

for health, both at the individual and the collective levels (Blane et al., 1996; Gregson, 2012).

An HIV competent community has six psycho-social characteristics (Campbell, et al., 2007; Campbell, Nair, Maimane, & Sibiya, 2008; Nhamo, et al., 2010): knowledge, social spaces for dialogue, a sense of community ownership of the problem and responsibility for tackling it, recognition of individual and local strengths for doing this, a sense of local solidarity around developing more effective community responses to HIV/AIDS, and partnerships with relevant support agencies outside of the community. Each of these is discussed in turn below.

Firstly, as stated above, programmes should seek to ensure that community members have the knowledge and skills necessary to respond effectively to HIV/AIDS. Secondly, they should work with local people to create safe social spaces for critical thinking about the causes of HIV/AIDS, obstacles to more effective responses, and how to avoid these. Here we are informed by Paulo Freire's (1973) notion of 'critical thinking' – which suggests that people are more likely to change their behaviour as individuals when working collectively with others (at best) to tackle the social circumstances that place their health at risk, or (at least) to develop strategies for alleviating their negative impacts. Freire argues that in conditions of deprivation and social injustice people commonly respond by viewing their negative life situations as the result of individual failings or bad luck. He argues that the development of understandings of the shared social causes of problems is a vital first step to the formulation of collective plans to begin to recognise and alleviate these.

Dialogue amongst liked and trusted peers may occur spontaneously in the course of indigenous forms of social participation – in local faith-based organisations or women's groups, or in daily peer networks of various sorts. It may also be purposively facilitated by health programmes using methods such as 'community conversations' (UNDP, 2004) or peer education (Campbell & MacPhail, 2002) with a carefully selected range of local groups representing different local interests. Community interventions have also used

initiatives such as sport and microfinance as arenas for promoting critical thinking about health. Such approaches train local community health workers to facilitate discussions where local people air reservations about new health programmes, 'translate' unfamiliar medical information about health problems or services into concepts and practices that make sense to them, brainstorm locally appropriate responses to health problems, and begin to put these into practice (Campbell and Scott, 2010).

Such collective debate and action is seen to support the third characteristic of an HIV-competent community, namely a sense of community ownership and responsibility for tackling HIV/AIDS, rather than more fatalistic style of waiting passively for outsiders to come to the community and solve the problem. It would also be essential for facilitating the fourth characteristic, recognition of individual and collective strengths to tackle the problem. Small-scale acts of kindness to the AIDS-affected will be invaluable in tackling stigma for example, and there is much that local community groups (e.g., church groups, patient self-help groups) can to do promote collective action to support more effective responses by local people. The fifth characteristic, a sense of local solidarity around tackling HIV/AIDS also potentially results from on-going community dialogue about local obstacles to respond and how to avoid them, as well as building on pre-existing local solidarity.

The concept of social spaces rests on the conceptualisation of dialogue developed by authors such as Billig (1987), Freire (1973) and Jovchelovitch (2007) who emphasise the key role of debate and dialogue in the processes through which peoples' sense of their possibilities for action are reproduced or transformed. Such spaces provide contexts where people can collectively work through doubts and uncertainties about taboo topics. Through a process of dialogue they can make this information relevant to their own lives – processing it in ways compatible with their pre-existing frames of reference, vocabularies and social practices. Dialogue amongst liked and trusted peers may occur spontaneously in the course of indigenous forms of social participation – in local faith-based organisations or women's groups, or in daily peer networks of various sorts. It may also be purposively facilitated

through approaches such as the ‘community conversations’ approach, where trained local facilitators work with local groups to further understandings of e.g. local cultural obstacles to change and to brainstorm locally appropriate ways of tackling these (Moulton, Miller, Offutt, & Gibbens, 2007; UNDP, 2004), HIV support groups where patients encourage one another to adhere to treatment and support one another in responding to stigma (Campbell, et al., 2011); participatory peer education (Campbell & MacPhail, 2002; Vaughan, 2010), interventions such as ‘Photovoice’ (Skovdal, 2011b; Wang, Yi, Tao, & Carovano, 1998) and the use of activities such as Microfinance groups (Kim et al., 2007) and sports (Jeanes, 2011) as the basis for opening up spaces for discussions about responding to HIV/AIDS. Such social spaces provide people with safe opportunities where they can talk about AIDS – still a taboo topic in many contexts – working with liked and trusted peers to develop critical understandings of obstacles to effective prevention and care, brainstorm ways they could respond more effectively, both as individuals and in groups, and generate awareness of the types of outside support they would need to optimise the effectiveness of their responses.

The latter point takes us to the sixth component of an HIV-competent community namely the need for communities to develop partnerships with outside organisations and agencies that are willing to support their efforts to improve their opportunities for health. Positive changes in the lives of the most marginalised are unlikely without significant support by powerful social actors and groups from both within and outside of communities, as well as their ‘political will’ to assist the most marginalised in improving their opportunities for well-being (Campbell, Cornish, Gibbs, & Scott, 2010).

The issue of partnerships has been relatively neglected in the theory and practice of HIV/AIDS related community mobilisation. Efforts have usually focused at the level of small-group activism and empowerment through small, bottom-up projects, usually involving narrowly defined marginalised groups. Such projects are often successful in building the skills and capacities of the poor, but less successful in building ‘receptive social environments’. Projects often assume that poor people themselves will be able to capture the attention

of the powerful once they have been empowered (Jones, 2001). Yet this is often not the case. The field of community mobilisation still has much to learn about how best to supplement their 'bottom-up' work with marginalised communities with appropriate parallel efforts to create receptive social environments in which powerful social actors are willing to heed the demands of the marginalised, and work with them to improve their opportunities for health and well-being.

This latter aspect of community competence is informed by the work of Bourdieu (1986) who argues that social inequalities are caused by the unequal distribution of access to empowering social networks. We extend this to argue that poor health in marginalised communities is closely related to poor peoples' lack of access to health-enabling social networks, presenting community health programmes with the challenge of not only mobilising community capacity and consciousness, but also to facilitate the development of social networks that enable effective community mobilisation - which Putnam (2000) and Woolcock & Narayan (2000) would refer to as bridging and linking social capital.

Case studies

It is against this background that we discuss two case studies of community mobilisation. Both sought to promote HIV/AIDS competence through building capacity, skills and confidence in a marginalised community, as well as developing 'receptive social environments' where more powerful groupings would be willing and able to support the community in working for better health. In many ways the projects are very different, but both have sought to empower very poor local people to cope with HIV/AIDS in rural African contexts. Both projects have been extensively written up elsewhere, and we draw on this literature to construct our argument in this chapter.

Building community HIV/AIDS competence: Home-based care in rural South Africa

Nature and context of problem

Entabeni is a rural community in KwaZulu-Natal, South Africa, about 30km from the nearest towns or hospitals. The first author was part of the Centre for HIV/AIDS networking (HIVAN), a university-based NGO located about two hours drive away. HIVAN's 'Community responses to AIDS' programme had a particular interest in developing approaches to HIV/AIDS management that sought to identify and facilitate indigenous community responses rather than imposing externally designed interventions. In 2003, HIVAN was invited to conduct research in Entabeni by a local resident's grandson, who was employed at the university, and deeply concerned about levels of HIV (36% of pregnant women were HIV positive at that time). He introduced the researcher to the local *Inkosi* (traditional leader) who agreed for the research to take place, and introduced HIVAN members to local volunteer health workers. The project had three phases: Research (2003), Dissemination and Intervention Design (2004), followed by a three-year intervention (2005-2008) (Campbell, Nair, Maimane, & Gibbs, 2009). In 2012, HIVAN researchers returned to the community to explore the long-term impact of the intervention on the community.

Entabeni is an isolated area, with no electricity or running water, and few tarred roads. Homesteads are dotted about a hilly and rocky landscape. Droughts in recent years have made it hard for people to make a living from subsisdence farming, and opportunities for formal employment are scarce. Many inhabitants are illiterate and not able to speak English. Access to television and radio is limited, and aside from HIV, residents suffer from high levels of tuberculosis and periodical cholera outbreaks. The *Inkosi* has an authoritarian leadership style, and local power relations are strictly dominated by adult males. Thus for example, women are expected to go down on their hands and knees when talking to the leader and his local representatives. Polygamy is common. Husbands pay lobola (bride-wealth) to their wives parents in exchange for their domestic and sexual services and as a result, women have relatively little power in intimate relationships.

HIVAN's baseline research in Entabeni (Campbell, et al., 2007a; 2008) found that the only support available to people dying of HIV/AIDS was offered by a group of about 80 volunteer home based carers, local women, usually unemployed, with low levels of literacy and English language skills. This group had arisen over a number of years, with very patchy and temporary inputs from various short term NGO and public sector community development initiatives. Their work involved walking from one homestead to another, often one or two hours apart up and down hills in intense heat, to assist the families and households of AIDS sufferers with rudimentary nursing, housework and prayer. They had a male leader who was paid a small salary by the regional Primary Health Care services to lead the group, but the women themselves worked with no financial support, little training and little recognition or input from local community leaders or the regional health and welfare services. They felt that their ability to perform their role was heavily constrained by their lack of even a basic stipend to cover their expenses, and by lack of recognition of the value of their work by other community members, in a context of high levels of denial of HIV/AIDS in the face of the terrible stigma that prevailed at the time (Campbell, Nair and Maimane, 2007b).

HIVAN researchers fed back their findings to a series of workshops with community leaders and organisations using a 'dissemination as intervention' approach, in which researchers reported back their findings to communities in workshops designed to facilitate local debate about how the community might turn their findings into put the findings into action in community-led initiatives (Campbell, Nair, Maimane, Sibiya, & Gibbs, 2012). At these workshops there was general agreement that the health volunteers played a vital role in assisting the AIDS-affected, and that this should be strengthened. The volunteers themselves said they were willing to take on an expanded role, but that they would require training and support to do this, as well as a stipend. They suggested that HIVAN members might assist them in expanding their work, and HIVAN agreed to play the role of 'External Change Agent' over the three-year period – putting the community in touch with potential training networks, and supporting them in setting up a project management committee that would include local public sector and NGO agencies in the health and

welfare sectors. HIVAN members were able to raise funding from a large US funder for a project which centred on a fairly standard 'empowerment via participation' approach to community development. Using the model of HIV/AIDS competence as its guiding frame, the project aimed to empower volunteer workers to lead an expanded community response to HIV/AIDS, supported by HIVAN in the first instance for a three year period, and thereafter run by the volunteers themselves. The proposal outlined three core activities aimed towards the development of a sustainable and community-led response:

(i) Empowering volunteer health workers to lead an expanded local response.

(ii) Assisting volunteers in mobilising support for their role from local people, particularly traditional leaders and men (who had traditionally given them little support) as well as young people. The project anticipated that the latter group would play a key role in helping in the delivery of an expanded response, given high levels of youth unemployment and the desire, expressed by many young people in the project's baseline research, for opportunities for skills building viewed as a bridge to formal employment.

(iii) Building partnerships between the community and outside support groups of various sorts. Each of these challenges are discussed below.

Empowering local volunteers to lead an expanded response

This aspect of the project's goals was relatively straightforward to achieve. The project was easily able to link the volunteer group to various NGOs offering training in the topics they asked for: home-based nursing, bereavement counselling, how to set up and run a small organisation, primary health care liaison, peer education to share these skills. NGOs appreciated the opportunity to engage with such a remote and hence 'hard-to-reach' community. The volunteers eagerly attended courses, and set up a cascade peer education system to share their new skills with other community members. The courses were backed up with high profile formal 'graduation ceremonies', where trainees received certificates followed by celebrations with food, singing and dancing. A local leader donated a disused building

which the volunteers set up as an outreach centre, where community members could come with HIV/AIDS related questions. As a result of this enhancement of their skills and profile, the volunteers felt a surge of joyful confidence, and a renewed commitment to their work.

Building local support for the volunteers' work

This was a slightly more complex challenge. Whilst the local *Inkosi* made every effort to facilitate the research and the intervention, his support raised a series of complex dilemmas (Campbell, 2010). Thus, for example, he instructed his 6 wives to attend an HIV awareness course run by the volunteers, and attended their graduation ceremony at the end of their training. His attendance at this event was a fantastic coup for the project, which sought to raise its profile in the community, and it was particularly well attended. However at the ceremony he gave a long speech eulogising the virtues of masculine sexual potency and female chastity, saying that whilst he had five girlfriends in addition to his six wives, and did not want to interrupt his God-given obligation to father children by using condoms, he knew that he was not in danger of contracting HIV/AIDS because his wives and girlfriends were virtuous and faithful. He drew approving cheers from men in the audience when he rejected the claim that polygamy caused AIDS, arguing that neither of the two groups most vulnerable to AIDS, gay men and youth, practised polygamy. Aside from this, the Inkosi's highly authoritarian leadership style, involving complete obedience by women and youth to adult men, also undermined the project's anticipated strengthening of the confidence of women and young people to provide strong community leadership of the local struggle against AIDS, and to protect their own sexual health (Campbell, Nair, Maimane & Gibbs, 2009).

Efforts to mobilise male support for the project were largely unsuccessful. There were at least three ways in which the project failed to resonate with macho masculinities. Men viewed caring for the sick and promoting health as women's work. They were extremely contemptuous of the activity of

volunteering, arguing that unpaid work held no dignity for men, and sneering even at women who were prepared to work to hard for no material gain. Finally, the project's emphasis on partner reduction and condom use contradicted associations of manhood with sexual insatiability and willingness to take risks (Campbell, et al., 2009). Similarly young people – who had expressed strong interest in project participation at the dissemination phase – were equally hard to mobilise. Detailed investigation suggested that they too did not see any dignity in unpaid work. Furthermore they said they had had their fingers burned in the past in projects that had persuaded youth to engage in volunteer work with false promises that volunteering would open up opportunities for paid work. It also emerged that rural youth had a dim view of their local surroundings, seeing the route to advancement lay in opportunities outside the community, and saving their energy for plans to get away rather than stay and strengthen their rural base (Gibbs, Campbell, Maimane, & Nair, 2010).

Across the community there was little support for women taking over leadership from the project from the older man, originally appointed by the Inkosi to run the volunteer team. When HIVAN periodically urged him to gradually delegate leadership responsibilities to women, he always agreed politely, but simply did not do so. HIVAN's one attempt to organise a confidential meeting of volunteers to develop a strategy for asserting themselves backfired when one of the volunteers broke ranks and told the male leader of the 'secret' meeting. His resulting fury terrified the women into continued submission. This led to great bitterness amongst the team, who felt that their hard work was not being rewarded by increased involvement in project decision-making.

Mobilising partnerships between community volunteers and outside agencies

The project had strong support from two small local one-woman NGOs (run by a Norwegian missionary, and a retired British businesswoman respectively) that ran on shoestring budgets and were able to be immediately responsive to community needs. They provided the bulk of the training of volunteers, served

tirelessly on the project's management committee, and were able to provide small sums of money to fund core activities (e.g. provision of furniture for the outreach centre, and meat and cold drinks for graduation ceremonies). They, together with HIVAN staff, also provided a sense of support and solidarity for the volunteers, with the NGOs, HIVAN and the volunteers serving as invaluable sources of recognition of the importance and value of each other's intensive efforts. Without the NGOs' assistance the project would simply not have survived. However these were small groups, with insecure funding, run by older women, so not a sustainable long-term project resources.

The project's greatest disappointment lay in its failure to get buy-in from public sector partners (Nair & Campbell, 2001). A key pillar of the project's rationale had been that over a three year period, formal involvement in the project's activities would become formally institutionalised into the job descriptions of health and welfare department officials in the region. This was a key element of the proposed long-term sustainability of the project. Prior to the project's start, senior public sector officials in the region had enthusiastically pledged commitment, viewing the project as a potential pilot study for the development of 'best practice' models that would create frameworks for them to implement high level national health and welfare policy commitments to increased community outreach in all aspects of their work. However, over time, this initial commitment did not translate into practice by the less senior public servants who should have been the ones to turn this commitment into action. Health and welfare department officials had no formal training in community outreach, so simply lacked the expertise to take this mandate forward. Whilst HIVAN was well qualified and more than ready to assist them in developing these skills, they appeared to be overwhelmed by the immense challenges of tackling health and welfare in under-resourced departments. They had little motivation to see poor community members as equal partners in their work in a highly status conscious environment. Moreover government departments were mired in red tape and a very rigid hierarchy, in which lower level civil servants were precluded from suggesting new or interesting action plans to their superiors. Yet they were the ones that had face to face contact with communities. Thus there were no mechanisms for 'bottom up' communication

of community needs and views to the supervisors who controlled the daily activities of public sector workers.

The second and possibly most key reason for public sector support of the project lay in the volunteers' very strong motivation to secure some small payment of their expenses and a small stipend for their work. The government had made vague promises that local home based carers would receive small payments, and one of the key aims of the project was that HIVAN would assist volunteers in securing these. However the state repeatedly changed the goal posts for such payment. Initially announcements were made that volunteers would be paid. After some time this was clarified further: namely that only volunteers with a school leaving certificate would get payments. This excluded the majority of the Entabeni volunteers. However even then when the small handful with school leaving certificates attempted to access the stipend they were old that they would need to register as a formal NGO, which involved many preconditions they could not meet. Some of the volunteers were older women supported by employed husbands and strong Christian convictions who saw the virtue of unpaid community service. However many others were desperately poor with children to support, and had been motivated to volunteer by the prospect of eventual payment. In such a context the drop-out rates of volunteers were very high. These two failures dented the project's prospects of long term sustainability beyond its three year life.

Another challenge facing the project was the withdrawal of its US government funding sooner than expected. Initially the funder had been very supportive of the project's slow community empowerment approach. However, halfway through the project's life a new funding controller was appointed in Washington DC, who decided that women's empowerment was "not a deliverable of value to the US government", and thus no longer appropriately funded by the agency (Campbell et al., 2009). Moving forward, programmes would be evaluated strictly in terms of 'numbers reached' and the production of context-free approaches and manuals that could be used in countries across the world The project was able to reduce its activities and string the funding out for longer than originally anticipated. Furthermore, the community

were extremely appreciative of the funding they did receive, which was put to good use in supporting local HIV/AIDS management activities over a three year period. However, in the face of the project's agenda to increase local peoples' HIV-related agency, this situation sent the community very clear messages that (a) the funders' primary accountability was to their own controllers, who had no interest in the community's own views of how best to proceed, and (b) that their hard work was controlled by far flung figures in another country with complete power to give money or take it away. This experience highlighted the strong contradiction inherent in the 'bottom up' policy rhetoric of community consultation, and the 'top down' reality of absolute funder power over activities.

Lessons and outstanding challenges

At the end of a three-year period when HIVAN withdrew from the project, morale was low and volunteers doubted if they had the confidence or commitment to continue alone. When HIVAN members returned to the community three years later, only a small handful of women were conducting home-based care, and the organisational support structure HIVAN had worked with them to establish was no longer in existence (Campbell, Maimane & Gibbs, 2012). There is no doubt that the HIVAN-supported Entabeni Project was extremely successful in mobilising a confident and enthusiastic group of volunteers during its three year life. It provided them with a range of new and highly relevant skills, including home nursing, bereavement counselling and peer education, all of which enhanced their ability to provide an expanded home based care service, as well as an active community outreach centre over the project's three year life (Mqadi, 2007). However it was less successful in creating a sustainable and community-led service beyond its funded life. Various resistances and obstacles – at the local, national and global levels – may have contributed to this. In summary, whilst the project had some success in building the skills and capacity of a small marginalised group of women to offer a valuable local welfare service, it was less successful in creating a social environment that supported them in using this new capacity to create a sustainable locally led response. Before

discussing this further, we turn to look at a very different project and arguably more successful community project in Kenya.

Building community HIV/AIDS competence: Supporting HIV-affected children in western Kenya

Nature and context of problem

Bondo District lies along the shore of Lake Victoria in the Nyanza Province of Western Kenya. The second author has played an active role in the District for several years, both as a researcher and as a consultant for a local NGO (WVP Kenya) and the Ministry of Gender, Children and Social Services. WVP Kenya is a youth-focused NGO that reaches some of the most vulnerable and HIV-affected children in Bondo District through partnerships with local community-based organisations (CBOs). Bondo has the highest prevalence of orphanhood in Kenya. Staff from WVP Kenya is from Bondo, have experienced poverty and disease first hand and speak the local language. They see vulnerable children best supported through local structures and knowledge systems, albeit in partnership with respectful and more resourceful organisations.

Bondo District is among the poorest districts in Kenya, with 68% living in poverty, with the majority surviving through subsistence farming and fishing. Homesteads are scattered across a varied landscape. Disease, particularly HIV and AIDS, is rife. Estimates of HIV prevalence in Bondo vary from 13.7%, which is twice the national average (NACC, 2006) to double the figure. One in three children have lost one or both parents and that one in nine have lost at least one parent (Nyambedha, Wandibba, & Aagaard-Hansen, 2003).

Many children in Bondo have to deal with hardship at a scale that is unimaginable to most people. As parents fall ill, children take on a caregiving role, which may include nursing (e.g., administering drugs, washing the parents and taking them to the toilet), household chores (e.g., cleaning, cooking and washing), and income and food generation (e.g., paid work for

neighbours, farming) (Skovdal, 2011a). Locally, engaging in such activities is often regarded as part of a child's socialisation in the community. However, in contexts of limited social support, caring duties can compromise a child's health, education and psychosocial well-being (Skovdal & Ogutu, 2009).

WVP Kenya is committed to seeing children as social actors and learning from their coping strategies – as a springboard for activities that seek to strengthen traditional support mechanisms that can further facilitate their resilience. This framework informed the 2nd author's baseline research into the coping strategies of HIV-affected children caring for their sick or elderly guardians. Using participatory research methods, like Photovoice, the study found that caregiving children cope through income generating activities, mobilising social support and constructing positive social identities (Skovdal, Ogutu, Aoro, & Campbell, 2009). However, the extent to which a child is able to cope depends on: i) the on-going negotiation between a child and its community in shaping social identities; ii) access to local support networks and resources; and iii) the quality of the community and its ability to share resources (ibid.).

To ensure that children are in a better to position to successfully negotiate access for support from their social environment in this context, WVP Kenya programmes and activities aim to support HIV-affected children in three ways: i) empowering local children (through scholarships and microfinance activities); ii) strengthening local capacity to support children (through community-based capital cash transfers); and iii) mobilising partnerships and supportive policy environments. These three foci will now be discussed.

Empowering local children

WVP Kenya empowers local children through three programmes. Firstly through combining sports activities and health education, it seeks to provide children and youth with a social space to discuss HIV and health-enabling behaviours. Secondly a scholarship programme identifies out-of-school

children in partnership with local community groups and provides them full school scholarships, including elements of household support where identified as necessary. A third programme works with HIV-affected and caregiving children and engages them in group-based income-generation activities. This programme arose as a result of the study on their coping strategies. Reflecting on the themes from the Photovoice exercise, the children, grouped into two youth clubs, were supported to collectively plan and implement activities to strengthen their coping capabilities and address some of their problems (Skovdal, 2011b). With social action funds made available from WVP Kenya, 14 children from one club started a maize selling business and 15 children in another club began rearing chicken and growing kale (Skovdal, 2010). Not only did the children gain access to food and small amounts of income, they also gained entrepreneurial skills and respect and recognition of their capabilities amongst local community members and guardians. WVP Kenya continues to support groups of caregiving children with social action funds.

Strengthening local capacity to support children

WVP Kenya recognises that even highly marginalised communities in Bondo have social resources that can support HIV-affected children. To utilise these, the programme builds children's and communities' participation into all their activities, and emphasises the need for agencies to support local communities. Therefore in addition to the above activities, which, target children directly, WVP Kenya also provides local CBOs with Community-based Capital Cash Transfers (CCCTs) to capitalise on their resources and strengthen wider community ability to support vulnerable children.

One community in Bondo, for example, after having reflected on local skills, resources and viable business opportunities, decided that they wanted to set up a social enterprise to provide services for events, like funerals, with the revenue supporting the some of the most vulnerable children in their community. The social enterprise was set up over a 3-year-period and

involved intensive training of community members on orphan care and support, children's rights and responsibilities, project management, book keeping as well as project specific training (e.g., catering). The first social action plan devised by the community asked for funds to buy a large marquee and plastic chairs to rent out during local events. This business required relatively little time and was cash generative. A year later WVP Kenya asked the community if their social enterprise could be expanded to increase their profit margin. The community developed yet another action plan, asking for funds to train as caterers, to buy catering uniforms and cookery utensils to offer their catering services, either together or separately from their marquee/chair business. Eight months later, WVP Kenya, with a remaining pot of money, asked the community for a last time if they could think of ways to expand their social enterprise. The community decided to buy a sound system complete with speakers and a microphone, which they could also rent out, either separately or together in a package with their catering, marquee/chairs services. This social enterprise was set up with $6,000 and has transformed the capacity of this particular community to provide for the needs of vulnerable children in their area.

Experiences from Bondo and beyond have found that this type of community mobilisation programme not only provides community members with the power and control to address the hardships experienced by children in their local area, but also offer recognition of, and confidence in, local knowledge, strengths and resources (Skovdal, Mwasiaji, Morrison, & Tomkins, 2008; Skovdal, Mwasiaji, Webale, & Tomkins, 2011). The programme helps sensitise the community to the needs and circumstances of HIV-affected children, placing a focus on their marginalisation, which in turn helps foster a sense of wider solidarity and unity for HIV-affected children, supported by their capacity to help them (ibid.).

Although CCCT has worked reasonably well in Bondo, it is by no means a magic bullet. Both WVP Kenya and the Ministry of Gender, Children and Social Services have experienced numerous difficulties in implementing CCCT, primarily relating to the notion of community. Community dynamics are

complex and characterised by competing agendas, interests and motivations. To minimise the risk of such dynamics undermining the success of CCCT, it has proved important to target communities that have a shared objective and members committed to implementing it, such as CBO members committed to assisting children in difficult circumstances. This is not the case in many communities.

In Bondo, the Ministry of Gender, Children and Social Services used project staff that had travelled the country to help with the facilitation of social action plans. With the best of intentions they facilitated workshops using participatory learning and action tools (See Rifkin & Pridmore, 2001) encouraging the communities to brainstorm ideas for their social enterprise. In the process they were giving examples of activities they could implement. Despite their intention to engage with communities as equals, their demeanours, dress code, level of education and experience, represented authority and power to the community members. When communities had to decide which projects to implement, rather than putting forward their own ideas linked to particular local strengths, they tended to 'decide' to engage in activities that were perceived to be prescribed 'from above'. They interpreted examples provided by the project staff as instructions which they dutifully incorporated into their social action plans. This misunderstanding unwittingly undermined the role of the project in creating opportunities for local self-determination and local experiences of control over project design and planning (Skovdal, et al., 2008).

Mobilising partnerships and supportive policy environments

Alliances between communities, NGO and donors

WVP Kenya has developed long-lasting and synergetic partnerships with a small number of European NGOs who provide the bulk of their funding. Their donors are committed to a long-term partnership with WVP Kenya that evolves in relation to the multiple and changing needs of vulnerable children in western Kenya. It is only because WVP Kenya has donors who understand

and share their interest in sustaining a long-term relationship with their target communities, hat they have been able to stay involved with their partner communities, supporting local efforts in their care of children and youth on an on-going basis.

WVP Kenya serves as a bridge between global donors and local beneficiaries, mediating between their very different realities. Although both the local and global actors share the same objectives (i.e. to improve the welfare of children and youth), their value systems differ significantly and they are accountable to very different stakeholders. This presents significant challenges for WVP Kenya who need to juggle donor reporting and expectations on one hand and local realities and values on the other. Being a local NGO, WVP Kenya tends to prioritise local values and therefore happily engages in a critical dialogue with its donors if they make recommendations for programme changes that not aligned with local values and are likely to come with unintended consequences. Not all global donors appreciate being challenged, let alone take the time to listen to local perspectives and make changes accordingly (Kelly & Birdsall, 2010). The donors who support WVP Kenya not only listen to what they have to say, but actively encourage on-going three-way dialogue between the donors, the NGO and their target community, about how best to 'do development'.

One recommendation that WVP Kenya contested with its primary scholarships donor came about after representatives from the donor agency came to Kenya and met some of the primary school girls they supported through WVP Kenya. To the donors' dismay they discovered that WVP Kenya had not given all their scholars a pair of shoes as part of their uniform. They were also unhappy about meeting scholars they had sponsored whose uniforms were torn and dirty. Unhappy about what they saw, they immediately recommended that WVP Kenya buy shoes for all their scholars and make sure the scholars always wear neat uniforms. Whilst WVP Kenya did indeed have money available to buy shoes and replacement uniforms for its scholars, in deciding not to purchase these items they were in fact being sensitive to the local context.

The children seen by the donor representatives went to schools in areas with extreme levels of poverty, where few parents can afford uniforms and shoes for their children. WVP Kenya felt that new shoes and uniforms would mark the scholars out as 'supported kids', which opened them to possible HIV-related stigma – given that most NGOs supporting children in Bondo focus on the impacts of HIV. Rather than just accepting the recommendation, WVP Kenya disagreed with the donor, who accepted their guidance on this issue. This example highlights not only the importance of partnerships in enabling local organisations and communities to respond to the needs of vulnerable children, but also the need for such partnerships to be rooted in mutual respect and learning, where communities are respected has having expertise of equal value to that of donors and NGOs (Apfell-Marglin, 1990).

Putting young care-giving on the policy agenda

Although young care-giving is a phenomenon known to practitioners and policy actors, little has been done practically to include caregiving children in existing programmatic responses and to include this particularly vulnerable group on the national or international policy agendas. In the interests of promoting awareness of the situation of children caring for their AIDS sick parents and influence wider institutional networks, WVP Kenya teamed up with the London School of Economics (LSE) and the Kenyan national Ministry of Gender, Children and Social Services in a project that sought to influence policy actors and practitioners at local, national and international levels – by transmitting community perspectives to more powerful policy actors (See Skovdal & Campbell, 2013).

This process started with WVP Kenya feeding back its research findings to local community organisations in Bondo – getting their own perspectives on how the types of assistance that would best enable them to offer support to caregiving children. These community perspectives and recommendations were in turn fed to a meeting of national policy actors and practitioners in Nairobi. The outcomes of the Nairobi meeting were fed to a forum of international policy actors in London. This multi-level engagement generated

new levels of awareness of the need to include caregiving children in policy and practice, framed by community perspectives on how best to do this.

Two key concerns emerged in these discussions, highlighting the potentially different value and knowledge systems characterising local-global encounters. The first was the view expressed by some that efforts should focus on abolishing young care-giving, and that efforts to support children in caring for their parents might unwittingly constitute support for child labour. The second was the concern that the ear-marking of care-giving children for special support might make them vulnerable to HIV-stigma (Skovdal & Campbell, 2013). These debates highlight the wider challenges that arise from seemingly straightforward efforts to promote multi-level dialogue on what initially seemed a fairly uncontroversial issue.

Reasons for success, outstanding challenges

WVP Kenya does not aim to create social change, but targets children's welfare directly (e.g., through scholarships, sports and health education) and indirectly (e.g., through community-based capital cash transfer). Either way, children are identified and supported through long-term partnerships with local community groups and organisation.

The head office of WVP Kenya is located in Bondo town and not Nairobi. Their staff are young, from the local area and speak the local language. They have experienced disease and poverty first hand and can relate to community members and children in ways that nobody from the outside can. They appreciate the importance of providing local community groups with access to valued resources, participation and self-determination in ways that optimise the agency and competence of community members – enabling them to support vulnerable children (Prilleltensky, Nelson, & Peirson, 2001). This however does not only apply to the NGO-community partnership, but also holds true for the donor-NGO partnership.

The work done by WVP Kenya is only possible because of the synergistic donor-NGO-community partnership. It allows WVP Kenya to stay involved with its partner communities and support them in a slow and incremental manner that strengthens their competence to care for HIV-affected children.

WVP Kenya faces two key challenges to their approach. Firstly, providing welfare to children does not come cheap and requires a steady source of income. Although they work carefully to ensure that none of their beneficiaries become dependent on them, and would like to see the community-run social enterprises as sustainable, they, in the provision of child welfare are not striving for sustainability. Secondly, their reliance on the donor-NGO-community synergy presents a limit to what they do. Few donors are willing to give local NGOs the kind of flexibility and control that WVP Kenya asks. Similarly, few community groups show the level of compassion and commitment to support HIV-affected children that WVP Kenya is looking for in their partner – excluding children who live in areas with no or poorly organised community groups. Despite successes, WVP Kenya face many outstanding challenges for the future as they seek to work with less coherent community groups and attract funds from more prescriptive donors.

Discussion

What are the social determinants of effective community mobilisation? We began this chapter by referring to three generations of HIV/AIDS strategies seeking to empower people to respond more effectively: information-based approaches, peer education and community mobilisation, targeting the individual, peer group and community as primary focus of change respectively. We criticised community mobilisation approaches for their narrow focus on empowering small marginalised groups with inadequate attention to creating wider contexts that support small groups in putting their newly acquired skills and confidence into action. Against this background we have reported on two very different case studies that have sought not only to empower marginalised groups but also to create social contexts that are supportive of their empowerment.

The Entabeni Project was ambitious, setting itself goals that would have required two sorts of fairly significant political changes in the social relations of a deeply conservative and neglected community. Firstly it sought to strengthen women's ability to lead and sustain a strengthened local response to HIV/AIDS in a highly patriarchal setting, in the context of a project focused primarily on supporting the highly stigmatised victims of an epidemic shrouded in fear and denial. Secondly it sought to implement an ambitious model of public sector-community liaison, through promoting partnerships between health and welfare officials and highly marginalised community members with no political or economic influence, in the context of a community so remote that many officials were initially not even aware of its existence, in an under-resourced public sector overwhelmed by the twin challenges of HIV/AIDS and poverty, with many public servants keen to distance themselves from settings of marginalisation that they themselves may have had to battle against in their own lives (Jewkes, 1998).

Whilst the Entabeni Project arose from a consultation exercise between community and NGO, its form was significantly influenced by western feminist ideals of 'empowerment via participation'. In order to attract funding, its plans were 'massaged' into a standard three year plan characteristic of many international donor funding cycles. Initially supportive of its social change approach, the project donor changed tack in mid-stream, withdrawing funding because the project did not conform to its increasingly strict emphasis on quantifiable 'deliverables' (numbers reached, the development of context-independent training manuals and so on).

WVP Kenya has implemented a far more successful project. To a certain extent, the degree of blame and shame attached to AIDS-affected children might be slightly less than that attached to 'sinful' and 'diseased' adults (Campbell et al., 2007b), leaving a child-focused community project with slightly more room to manoeuvre. However, this observation teaches us fewer actionable lessons than attention to WVP's style of response which differed from Entabeni's in at least three significant ways. Firstly, WVP has never had

any kind of social change agenda. Its aim has always been very clearly a small-scale welfare one: to assist a finite number of children to cope with the burdens of nursing sick parents in conditions of desperate poverty, and to enable them to access the education that will make a very significant difference to their future life chances. Secondly the project developed from more realistic expectations, guided by an ethos to provide children and youth with opportunities to fulfil their potential in an organic and very cautious way, which did not involve any kind of 'grand vision' beyond what could be achieved by particular children from one day to the next. Thirdly, the project has been blessed with funders who were completely willing to respond to the needs of the project and the community as they arose, with definitions of success continually negotiated between funders, NGO and community, with such negotiations focusing on concrete achievements on a case by case basis rather than any preconceptions of what would constitute an acceptable outcome.

WVP Kenya seems also to have operated with an intuitive understanding of Wieck's (1984) principle of 'small wins'. Wieck argues that community programmes should focus on achieving 'small wins' as early stepping stones to long-term and more ambitious changes. He would urge caution to those seeking to define problems (e.g. lack of home based care in Entabeni) in terms that are too wide for a small NGO funded community project to achieve realistically in a short time span (e.g. the empowerment of women to lead a local AIDS response in a strongly conservative and male dominated setting). From Wieck's perspective, it is most helpful for projects to start by identifying relatively quick, tangible first steps as WVP did (e.g. helping 100 children buy school uniforms) – goals that are only modestly related to grander political outcomes (e.g. challenging the social marginalisation of children in conditions of poverty). Small-scale successes then provide a material and experiential basis for more ambitious future action over time (Alinksy, 1973). Ironically, in retrospect, Entabeni did indeed achieve many 'small wins', providing effective home-based care and support to AIDS-affected households and so on over a three year period. However the project rhetoric excluded the inclusion of these achievements as significant successes, no doubt contributing to a

disappointed sense (both in the community and in the NGO) that the project had not been as successful in achieving its goals as it might have been. Furthermore the project simply wasn't conceptualised in the gradual and long term evolutionary way that framed WVP Kenya.

The comparisons above support our growing calls for the need to rethink how best to use concepts such as 'critical thinking', 'empowerment' and 'gender' in the social development context (Campbell and Cornish, in preparation). Whilst we are fully sympathetic with the spirit of 20th century critical theory which framed the development of these terms, in many ways they have outlived their usefulness and require dramatic reformulation. Thus for example, critical gender theorists are increasingly referring to the poor resonances between western liberal notions of gender and women's empowerment, and the experiences and aspirations of marginalised African women – citing these as partial explanations for the dismal failure of many 'gender mainstreaming' efforts to improve the lives of oppressed women in the HIV/AIDS and other contexts (Amide Obiora, 2003: Bates et al., 2009; Mannell, 2010;). Critical human rights thinkers (e.g. Englund, 2006) highlight ways in which concepts such as 'empowerment' and 'participation' often serve as blunt tools for critical political analysis and action because of an emphasis on the civil or political rights of the excluded – an emphasis that completely neglects the fact that economic inequalities and poverty often make it extremely unlikely that new civic and political entitlements would increase people's capabilities to lead the lives they would choose to lead (Seckinelgin, 2012).

In many ways, the WVP project was not shackled by these conceptual framings in the way that Entabeni was. Neither was it imprisoned by the constraints of accepting money from large external funding bodies whose primary loyalties, sense of accountability, and shifting agenda's over time are determined by western decision-makers who prioritise the interests of their own countries and constituencies over the communities that they claim to serve. To date, WVP funders have been particularly sensitive to the need for local-global partnerships in which communities and outsiders are seen as equal partners, bringing different forms of local and technical expertise in

programme design, implementation and evaluation. They also acknowledge their responsibility to long-term engagement in on-going ‘relationships for aid’ (Eyben, 2006), where community, NGO and funder are locked into on-going dialogue about how best to proceed to optimise community opportunities for well being.

Conclusion

There is an urgent need for a ‘fourth generation’ of approaches in HIV/AIDS research, one which pays greater attention to those dimensions of wider social context that support or undermine efforts to empower poor communities to respond more effectively to HIV/AIDS (Campbell & Cornish, 2010). There is a need for increased documentation of factors that enable or limit efforts to build community HIV/AIDS competence – through more case studies of particular interventions in particular settings. In-depth case studies of projects in real settings potentially provide fertile spaces for critical activists to pay closer attention to the contexts of programmes, with particular emphasis on the ‘spaces of engagement’ opened up by externally funded interventions in highly marginalised communities (Campbell, Cornish & Skovdal, 2012), accumulating more detailed examples of real projects to examine the contexts that best open up or close down opportunities for the development of community HIV/AIDS competence in marginalised groups.

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