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Building contexts that support effective community responses to HIV/AIDS: a South African case study.

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Abstract

In this paper we discuss our conceptualisation of a ‘health-enabling social environment’, and some of the strategies we are currently using to build social contexts most likely to support effective HIV/AIDS management in southern Africa. In developing these ideas, we draw on our on-going collaboration with residents of Entabeni, a remote rural community in South Africa where 43% of pregnant women are HIV positive. The aim of this collaboration is to facilitate contextual changes that will enable more effective community-led HIV/AIDS management in an isolated area where people have little or no access to formal health or welfare support, and where HIV/AIDS is heavily stigmatised. We give an account of the three phases of collaboration to date. These include research; the dissemination of findings and community consultation about the way forward; preliminary project activities (skills training for volunteer health workers; partnership building and a youth rally) as a way of illustrating what we believe are six key strategies for facilitating the development of ‘HIV-competent’ communities: building knowledge and basic skills; creating social spaces for dialogue and critical thinking; promoting a sense of local ownership of the problem and incentives for action; emphasising community strengths and resources; mobilising existing formal and informal local networks; and building partnerships between marginalized communities and more powerful outside actors and agencies, locally, nationally and internationally. We discuss some of the triumphs and trials of this work, concluding with a discussion of the need to set realistic goals when working at the community level in highly conservative patriarchal communities to tackle problems which may be shaped by economic and political processes over which local people have little control.

Introduction

HIV/AIDS continues to ravage many parts of sub-Saharan Africa, bringing untold suffering to millions and threatening many fragile development gains (Barnett and Whiteside, 2002). To date, little hard scientific evidence exists for sustained positive impacts of interventions (Gregson, Adamson, Papaya et al., 2005). Most interventions have been biomedical or behavioural in orientation, imposed on communities by outside experts. Billions of dollars have been poured into programmes concerned with HIV-awareness, behaviour change, condom provision, STI treatment, voluntary counselling and testing, partner tracing, the treatment of opportunistic infections and, most recently in some settings, anti-retroviral therapy.

In explaining disappointing program outcomes, reference is often made to various aspects of the social environment that prevent vulnerable groups from making the best possible use of HIV/AIDS interventions (Barnett, 2002; Tawil, Verster & O-Reilly, 1995). There is growing recognition that the implementation of discrete programs aimed at delivering services to vulnerable groupings is likely either to fail, or not be sustained in the long run, if the surrounding context and supporting systems do not shift in ways that support the goals of program efforts. In relation to our interest in the local community level of analysis and action (Campbell and Murray, 2004) a growing number of empirical studies highlight the failure of many interventions to take account of the way in which local community relations may support or hinder the possibility of program success (Campbell, 2003; Gruber & Caffrey, 2005; Pfeiffer, 2003).

At the level of rhetoric, it is increasingly common to hear of the need to build health-enabling community contexts. However, much work remains to be done in developing *conceptualisations* of what would constitute such environments, and *practical strategies* for promoting them. We address this challenge in the current paper, which reports on our on-going efforts to develop the concept of an 'AIDS-competent community' through our current involvement in designing and implementing a research-led 'community strengthening' intervention in South Africa.[1]

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[1] A community is usually defined either as a group of people who share a common social identity, or as a group who live in a common geographical space. In practice – for reasons relating to place-based resource allocation and convenience – health interventions usually target their efforts at geographically defined communities. This is particularly the case in geographically remote areas such as the one discussed in this paper. As a result, we use this place-based notion of community in our work.

Through our work for HIVAN[2], an HIV/AIDS research and networking organisation in KwaZulu-Natal, South Africa, the authors of this paper (hereafter referred to as the 'HIVAN team') have spent the last 18 months working in partnership with residents of an isolated rural community in which 43% of pregnant women are HIV-positive (HEARD, 2005). The aim of our project is to build AIDS-competence through working with local people to identify obstacles to effective HIV/AIDS management, and to develop strategies which they can use to support one another in responding to the epidemic, and be more effective in accessing help and support from outside the community.

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 (a key obstacle to effective HIV/AIDS management, often deterring people from accessing prevention and care services); support for people living with AIDS and their caregivers; co-operation with volunteers and organisations seeking to tackle HIV-prevention and AIDS-care; and effective accessing of health services and welfare grants, where these exist.

The aim of this paper is (i) to outline six key psycho-social resources that we believe need to be developed by those seeking to build AIDS-competent community contexts, and (ii) to illustrate the way in which we have used our conceptualisation of AIDS competence to inform our on-going involvement in the design, implementation and evaluation of an intervention to facilitate local community responses to HIV/AIDS in a deep rural area in South Africa.

In terms of the systems change focus of this *Special Issue*, we see our work as a 'systems change intervention' insofar as we seek not only to empower individuals, but also to promote the development of social networks and relationships – both inside and outside of the community – that are most likely to support and sustain the psycho-social changes we believe are necessary to enable community members to respond most effectively to HIV/AIDS. We interpret the word 'systems' to mean the types of bonding and bridging relationships that are most likely to facilitate the development of AIDS-related knowledge and skills, safe social spaces, a sense of

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[2] HIVAN is a university-based NGO, devoted to developing research and practice in the field of HIV/AIDS networking. http://www.hivan.org.za/gettoknowus/team.asp#dI

ownership of and responsibility for the problem of HIV/AIDS, and an appreciation of local strengths. This point is taken up again in the penultimate section of the paper.

We hope that our account of the concepts and strategies discussed below will be useful not only for those working in areas with high levels of HIV/AIDS, but also much more widely for those working to create community contexts that support the possibilities of health in any marginalized setting. The issue of the generalisability of case study findings is a controversial one. Some argue that its is not possible to generalise case study findings. Others argue that generalisability from one context to another is possible, with decisions about generalisability dependent on the expert ‘human judgement’ of experienced social researchers (Flyvberg, 2001). Others argue that whilst case studies cannot yield ‘empirical generalisation’ from one social setting to the next, case investigations gain their generality through generating useful concepts that are relevant to a range of contexts (Cornish, 2004) Concurring with both Cornish and Flyvberg, we hope that colleagues working in a range of countries and contexts will benefit from our on-going efforts to develop conceptualisations of health-enabling social environments, and of our account of the strategies that we are currently using for developing such environments.

Context: HIV/AIDS in Entabeni, South Africa

We begin with an overview of the context of our work, before proceeding to elaborate on our conceptual framework and intervention strategies. Entabeni[3] is 30km away from the nearest town or hospitals. Access to health and welfare services is limited because there are few roads, and because people often lack money for transport. There is no clean water. Cholera and tuberculosis are rife in addition to HIV/AIDS. Adult illiteracy is high as are unemployment and poverty. Most depend on subsistence farming, but this is difficult with droughts and the hilly landscape. The area is centrally controlled by a traditional chief who often has to travel away from the community, delegating power to local ward leaders, many of whom describe themselves as lacking in confidence and leadership skills. Power structures are patriarchal, men practice polygamy and women have little power to protect themselves in sexual relationships.

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[3] Entabeni is a pseudonym for our community of interest.

Much has been written about the way in which the African AIDS epidemic is driven by power inequalities between youth and adults, and between men and women (Campbell, 2003; Campbell, Foulis, Maimane and Sibiya, 2005). These inequalities are particularly severe in this very conservative and remote community, where people have little access to education or to new ideas of any kind.

At the time of writing (mid-2005), the South African government is slowly starting to make antiretroviral drug treatment available to people with full-blown AIDS (with a CD-4 cell count of less than 200). However, for reasons relating to hospital access and poverty, at the time of writing ARVs remain a dream for the majority people with AIDS in this impoverished and isolated place, with AIDS still almost certainly being a death sentence for the majority of those affected.

Informal care, within impoverished households, generally by women, tends to be the only support available to most people dying of AIDS. Patients and caregivers are burdened by lack of money, food and transport to hospitals. Many lack other basic resources for home nursing (gloves, bedding and clean water). They suffer tremendous isolation given the stigmatisation of AIDS, which makes people reluctant to disclose their status, often even to their caregivers. The burden of care is often the final straw for already over-extended rural women, some of whom are also sick themselves. Caring for an AIDS patient in the final stages (who may, for example, have diarrhoea 10 or 15 times a day), with no water, no bed linen and no nursing skills, and with little health and welfare support of any kind, puts caregivers at risk of physical and psychological burnout, family breakdown and the destruction of household economies (Campbell and Foulis, 2004; Rugalema, 2000).

The main source of help to people with AIDS and their caregivers in this area is a group of volunteer health workers who visit AIDS-affected households providing basic nursing assistance and emotional support (Maimane et al., 2004). This is an uneven group of 80 local residents (nearly all women with little or no education). They have varying talents and skills. Some, but not all, have rudimentary training in home nursing through the unsystematic and temporary inputs of occasional government programs and NGOs, as well as a single overseas missionary who has spent two years in the community with a miniscule grant, engaging in various social development activities, including the construction of a simple hospice which is able to assist a small number of people dying of AIDS.

The volunteers are led by an inspirational group leader, born in the community. We refer to him as the ‘volunteer leader’ in this paper. He spent 20 years away from the community, during which time he received training in home-based care, on a course run by a national non-governmental organisation. On his return to the community, he used these skills to mobilise this team of volunteers. This is a ‘bottom-up’, community-led and community-owned initiative, completely resourced by local volunteers.

The volunteers are remarkable for their dedication and commitment, and their willingness to work incredibly hard for the smallest of gains. Whilst a minority of them receive small stipends from various sources, most work for no pay, with few skills, having to walk long distances on foot, up and down steep hills, often in searing heat, to households which may be several kilometres apart. After long walks to households, volunteers may sometimes be turned away by families who refuse to admit they have a relative with HIV/AIDS. Their work is arduous. It includes fetching firewood and water, cooking, cleaning patients and in extreme cases supervising the transport of patients in wheelbarrows or on relatives’ backs to the nearest roads to seek transport to hospital. Even when people do manage to get to hospitals, due to overcrowding and lack of resources in rural hospitals, swamped by the AIDS epidemic in addition to a range of other challenges, people are seldom admitted, at best being given symptomatic treatment for opportunistic infections and then sent home.

For those who prefer African traditional medicine, the area has many indigenous traditional healers, treating their patients through herbal and/or spiritual methods. Some claim to be able to cure AIDS, leading to disappointment for desperate families. Others offer various forms of psychological support and nutritional advice.

The AIDS-competent community

What are the preconditions for an AIDS-competent community as defined in the introduction to this paper? A detailed analysis of our Entabeni case study data in the light of both (i) the community heath literature; and (ii) our own previous involvement in the design and evaluation of community-led HIV/AIDS interventions (Campbell, 2003; Campbell, Foulis, Maimane and Sibiya 2004, 2005) has led us to our six-factor conceptualisation of the psycho-social resources whose presence or absence serves to facilitate or hinder AIDS competence. We believe that this model provides a useful starting point for those seeking to develop strategies to facilitate AIDS-competent community contexts.

Our work resonates with a number of trends in American community psychology. Most importantly we locate ourselves firmly within the tradition of community-based action research (Israel, Eng, Schultz *et al*., 2005; Minkler and Wallerstein 2003). All our work is conducted in partnership with research communities, with the explicit aims of working collaboratively with local people to identify possibilities for action towards improved health and well-being, and strategies for implementing such action.

We also locate our work within the context of on-going debates about how best to create social settings that enable health. Broadly speaking, the goals of our work are very much in the spirit of Kelly's ecological approach to community psychology (2006; Kelly *et al*., 2000) with its emphasis on the importance of developing settings that support individuals in building both personal and social resources to address pressing life challenges.

Turning to the more specific goals of our work, our efforts are consistent within the spirit of Cottrell's (1964, 1976) and Iscoe's (1974) quest to give actionable content to the concept of community competence. In their work, members of a 'competent community' are able to collaborate effectively in: identifying their problems and needs; setting goals, priorities and action plans; and working collectively to implement these. As will become clear below, we see our work as building on these foundations through our identification of the psycho-social drivers of the types of collaborative decision-making and action that would constitute 'community competence' in our particular context.

In this respect our work also contributes to on-going debates about developing actionable conceptualisations of 'empowerment' (Schulz, Israel, Zimmerman *et al*., 1995) that are appropriate and useful for informing health and community development work aiming to promote particular forms of community competence in specific contexts. Here we align ourselves with Wallerstein's (1993) definition of empowerment which draws heavily on the work of Paulo Freire (1970, 1973). She conceptualises empowerment as a social action process through which members of marginalized communities participate in collective activities that lead to increased individual and community decision-making and control, in the interests of improving their quality of life. We believe that the six dimensions of AIDS-competence that we outline below provide a useful conceptualisation of the psycho-social drivers of HIV/AIDS-related empowerment in rural South Africa.

The lengthy process of researcher-community engagement outlined below has resulted in a large qualitative data set, including (i) more than 120 long interviews and focus group discussions with a wide-range of HIV/AIDS relevant actors both inside and outside of the community, as well as detailed fieldworker diaries, over the course of the 18-month period reported on in this paper; (ii) our participation in informal face-to-face discussions of possible action plans with potential Project partners; as well as (iii) our involvement in the on-going formal partnership meetings discussed below. We plan to report on our analysis of this material in a rolling series of papers to follow. The aim of this – our first paper on this work – is to present a ‘birds eye’ overview of the first 18 months of our engagement with this community. We do so in the interests of highlighting the over-arching conceptual framework which is simultaneously informing and being refined through this on-going work.

Conforming to linear protocol of an academic paper, we provide an account of our conceptual framework at the beginning of this paper. However, we must emphasise that this framework represents the evolving conceptualisation that has emerged over the course of the community engagement we outline below. Whilst this framework has its roots in our earlier work on HIV/AIDS in other South African contexts cited above (Campbell, 2003; Campbell, Foulis, Maimane and Sibiya 2004, 2005), it has been considerably honed and fine-tuned through our practical experience in Entabeni. As such, the framework is as much the *outcome* of the community engagement presented in this paper as the *starting point*.

Our account of the six psycho-social resources whose presence or absence serves to facilitate or hinder AIDS competence are as follows:

Knowledge and skills: community members should have the knowledge and skills necessary to avoid HIV-infection, to provide the best possible care and support to people with HIV/AIDS, and to access whatever forms of health and welfare support are available.

Safe social spaces: People should have opportunities to discuss HIV/AIDS with peers in face-to-face settings (Low-Beer and Stoneburner, 2004), which we refer to as ‘social spaces’. At this stage of the epidemic, people usually have basic information about the disease. However it is often presented in unfamiliar ways that they cannot ‘translate’ into concrete action plans in their own lives. Here we are inspired by Ethiopian method of ‘community conversations’, using trained local facilitators to help people identify obstacles to effective HIV-prevention and AIDS-care and discuss how they can work together to tackle these (UNDP, 2004).

Ideally such social spaces should provide settings in which people can engage in debate and dialogue about HIV/AIDS, a taboo topic in contexts of denial and stigma, for a number of reasons: there is simply a need to ‘break the silence’ around HIV/AIDS; there is a need to share factual information about AIDS; there is a need for opportunities to ‘translate’ factual information about HIV/AIDS into concrete action strategies that people can apply in their own lives; and there is a need for arena’s in which critical thinking can take place to facilitate change.

In relation to the final point, we believe that social spaces are vital to enable people to diagnose and debate obstacles to effective responses to HIV/AIDS, and to share ideas about ways in which they might overcome these. Here, we draw on Freire’s (1970, 1973) concept of ‘critical thinking’: people are most likely to develop health-enhancing attitudes and behaviours when they have the opportunities to collectively engage in dialogue about the obstacles to behaviour change, and about ways in which they might – individually and collectively – act to resist such obstacles. Drawing on Habermas’ (1992) idealised concept of the public sphere, we believe that such conditions are most likely to be met in conditions where participants in debate meet as peers, engaging in discussion in conditions of equality, and where ideas are evaluated in terms of the sense that they make to the participants, rather than in terms of the extent to which they support the status quo.

Ownership and responsibility: The third characteristic of an AIDS-competent community is one where people have a sense of ‘ownership’ of the problem, and a sense of responsibility for contributing to its solution (Campbell, 2003). Fear, denial and stigma drive the disease underground, deterring effective accessing of HIV/AIDS information and services, and undermining the humane treatment of people living with HIV/AIDS (Campbell, Foulis, Maimane and Sibiya, 2005). Even when people acknowledge the existence of HIV/AIDS, they may respond passively, waiting for outsiders from government or NGOs to come and tackle it, not acknowledging that they too need to contribute to solutions.

Confidence in local strengths: This refers to local peoples' confidence in their individual and group strengths to make an effective contribution to tackling HIV/AIDS, and their sense of agency to action these strengths (Kretzmann and McKnight, 1993). In situations of poverty or other severe life challenges, people sometimes experience problems as overwhelming, viewing themselves as helpless victims and losing sight of the immense resourcefulness and ingenuity that they have used to survive (Sliep et al, 2003, 2004). A key challenge in building AIDS-competent communities is not only working with people to identify and name the problem of HIV/AIDS and its causes, but also in identifying individual and collective strengths for addressing it. Individual efforts might involve helping AIDS-affected families with housework, or simply showing kindness to people with AIDS in chance encounters. At the group level, local churches or youth clubs might facilitate local responses. Churches might offer spiritual support to affected families, or educate members about HIV/AIDS. Youth clubs might organise groups to help caregivers with basic tasks such as collecting water or firewood. Groups might also put pressure on local leaders to get more actively involved in acknowledging the problem of HIV/AIDS and assisting local responses in whatever ways they can.

Solidarity: An AIDS competent community is one characterised by a sense of within-community solidarity that some people refer to as 'bonding social capital' (Saegert et al., 2001).[4] We believe that people are most likely to work collectively to achieve goals of mutual interest (in this case more effective HIV/AIDS management) in the context of trusting and supportive relationships. Such relationships also provide the optimal context for the (i) effective dialogue in safe social spaces, (ii) sense of ownership and responsibility for tackling HIV/AIDS, and (iii) sense of confidence and agency in relation to local strengths that we refer to above. It is also within such communities that people are most like to challenge the stigmatisation of people with HIV/AIDS and to treat them and their families with respect and dignity, creating a more supportive context for AIDS-care. In relation to HIV-prevention, it is within such humane conditions that HIV-vulnerable people are less likely to respond to the

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[4] We use the term 'social capital' with some caution, given the critique that Putnam's (2000) popular definition of this term directs attention too narrowly to the community level of analysis, ignoring the impact of wider political and economic determinants of social problems. In our work we use Bourdieu's conceptualisation of this term, because of Bourdieu's (1986) sensitivity to the way in which access to social capital is shaped by such economic and political factors (amongst which gender, poverty and stigma/symbolic exclusion would feature strongly in our community of interest).

epidemic with fear and denial, and more likely to feel confident to seek out information about prevention and/or testing.

Bridging partnerships: An AIDS-competent community is one where people work to build ‘bridging’ relationships with networks and agencies outside the community who have the political or economic power to facilitate effective local community responses to AIDS (Evans, 1996; Campbell, Foulis et al, 2005). Communities that lack networking skills often miss opportunities to generate support from partners in the public sphere (government health or welfare departments), the private sector (such as local employers) or civil society (such as AIDS-related NGOs or regional youth or women’s groups).

It is this evolving six-point conceptualisation the psycho-social preconditions for an AIDS-competent community that we use to frame our community-strengthening programme in partnership with Entabeni residents – in the sense that we see our contribution as explicitly seeking to facilitate each of these six psycho-social processes in the intervention. In the following section we outline the three phases of our involvement in this intervention to date.

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Strategies for the development of an AIDS-competent community:

- **Building knowledge and skills**
- **Creating safe social spaces for dialogue**
- **Promoting ownership and responsibility**
- **Building confidence in local strengths, and agency to mobilise these**
- **Building solidarity (‘bonding’ relationships)**
- **Building partnerships (‘bridging’ relationships)**

Facilitating community responses to HIV/AIDS

Phase one: research

The HIVAN team first entered the Entabeni community as researchers in early 2004, as part of their brief to conduct case studies of community responses to HIV/AIDS in KwaZulu-Natal. They were introduced to the area's traditional chief by a colleague who had relatives in this community, and was concerned about the high levels of death and suffering in the wake of the AIDS epidemic. The traditional chief arranged for the HIVAN team to meet the volunteer health worker leader, giving him permission to facilitate our work in Entabeni. On this basis 60 in-depth interviews and focus groups were conducted with a wide range of local people, as well as health and welfare professionals, missionaries, NGO workers and business leaders in the surrounding region.

We have already provided a thumbnail overview of the Entabeni community above. Within this context, our assessment of Entabeni in the light of the six components of an AIDS-competent community was as follows: People had patchy *knowledge* about HIV-prevention and poor AIDS-care skills. Fear, denial and stigma meant that there were virtually no *social spaces* in which people could openly discuss HIV/AIDS and how to respond to it. There were low levels of *ownership* of or responsibility for addressing the problem in a demoralised community with few links to the outside world.

People saw HIV/AIDS as overwhelming, with little sense of individual or community agency to tackle it. There was little recognition of local *strengths*, in particular the efforts or value of the volunteer health workers. The stigmatisation of HIV/AIDS made many people reluctant to have any contact with the volunteers, or even to acknowledge their existence, lest other community members suspected that they or family members might be HIV-positive. When asked who should solve the problem of HIV/AIDS, people tended to say that 'the government' should tackle the problem, but people often only had a vague sense of who or what the government was. In terms of bonding social capital, high levels of denial, stigma and secrecy had undermined the likelihood that local people would come together to develop effective community-level responses to HIV/AIDS.

Despite these challenges, the community did indeed have remarkable strengths in the face of HIV/AIDS: particularly the love and commitment of family members caring for dying relatives and the dedication of the volunteer health workers, working tirelessly with few skills and little recognition. Furthermore, several groups expressed their willingness to become more involved in HIV/AIDS management efforts, but said they lacked the training and confidence to do so. These included young people (in and out of school), and some (but not all) local ward leaders and religious leaders.

In terms of *bridging social capital*, people had few links with outside sources of help. As already stated, most lacked the skills and resources to access welfare grants and geographically distant hospitals. However, in planning our case study, we scoured the region around the community for potential ‘partners’ – by which we meant the nearest possible actors and agencies in the wider geographical region who might be mobilised to support the community in any way. As discussed at length below, we found a number of individuals and groupings who expressed an interest in working in remote rural communities, provided they were furnished with some way of accessing such communities, which had proved too difficult to date. One poignant example of the difficulties people had faced was given by a Catholic nun who supports volunteer health workers and does hospice work in an adjacent community. She said she had gone to the top of one of Entabeni’s thousands of hills and tried to shout – as a way of attracting the attention of local people who might be interested in working with her. After a poor response to her shouting, she had decided to give up on Entabeni and place her energies in more accessible workplaces.

Phase Two: Dissemination of research findings and community consultation.

The second stage of our engagement with the community took the form of a series of research dissemination workshops in late 2004 and early 2005. The aims of these workshops were two-fold. Firstly we sought to feed back the findings outlined in the previous section of this paper to community – highlighting the challenges that we believed would need to be addressed to enable people to respond more effectively to HIV/AIDS.

In designing our feedback workshops we sought to do more than report back the research findings. At that time we did not know if we would succeed in our application for funding to become more involved in HIV/AIDS management work. For this reason we developed a ‘dissemination as intervention’ model, with workshops designed to feed back research findings in ways most likely to facilitate what we regarded as the six features of an AIDS-competent community: knowledge, social spaces for dialogue, ownership/responsibility of the problem and confidence in strengths to respond, as well as bonding and bridging social capital.

The workshop had four sections: (i) building HIV/AIDS-relevant knowledge; (ii) discussing the impact of AIDS on the local community, as well as obstacles to meeting patient and carer needs; (iii) identifying and building on existing community strengths; (iv) formulating possible individual and group contributions to more effective local HIV/AIDS management. Apart from section (i) where input came from group participants alone (see below), the other three sections began with a brief input from the researchers outlining our research findings, followed by small group discussions of the implications of the findings for possible local action.

We facilitated workshops with nine groups of local residents: health volunteers, religious leaders, traditional leaders, traditional healers, school learners, young people out of school, members of a local sewing group, teachers, and a local development group. One of the aims of the workshop was explicitly to get people to think through ways in which they could mobilise limited local strengths and resources to deal with HIV/AIDS, and to counter the tendency to wait for outside experts (e.g. the government) to take control of the problem. Here we were motivated not only by our interest in facilitating a sense of local ownership and agency in relation to HIV/AIDS, but also because the likelihood of this happening without significant intervention was limited by a combination of public sector resource constraints and the remoteness of the area. For this reason, these nine groups did not focus specifically on the fifth component of an AIDS competent community, namely building partnerships with potential support agencies outside the community, although this is a key goal of the overall project. The potential role of partnerships was a central focus in a 10th dissemination workshop however, which brought together volunteer health worker representatives, local community leaders and a group of potential ‘partners’ in the public and private sector agencies located closest to the community (discussed later in the paper).

To what extent did the workshops succeed or fail in contributing to their objectives of promoting AIDS competence? As stated above, the first phase of the workshop focused on building <u>knowledge</u>, through providing opportunities in which people could consolidate the fragments of knowledge that they had between them. This involved dividing workshop participants into small groups to discuss the causes of HIV/AIDS, before reporting back to the plenary. For two reasons, our workshop policy was that workshop facilitators (members of the HIVAN team) would not interrupt, or seek to ‘correct’ what they regarded as any misconceptions that arose in the course of the group discussions. Firstly because we sought to run workshops which provided opportunities for participants to ‘process’ information about HIV/AIDS in ways that made sense to them within the framework of their own worldviews and possible worlds. Secondly because we sought to facilitate knowledge-building in such a way that participants would feel a sense of personal ownership of any knowledge they acquired in the discussions – and thus be more likely to retain and use it – than would be the case with knowledge seen as ‘other’ and the property of experts from outside the community, as our research suggested had been the case in the past.

Some regard this as a controversial strategy, opening the risk that workshop facilitators will knowingly allow participants to leave with inaccurate or poorly formulated knowledge. Although we were prepared to take this risk, for what we felt were the two more important reasons outlined above – we need not have worried. Although some small group discussion participants did make comments that facilitators might have regarded as ‘incorrect facts’, in every case these ‘misconceptions’ were confidently challenged by other group members, resulting in plenary feedback sessions which were more or less accurate.

In the feedback sessions after the workshop, workshop participants repeatedly said that the most valuable aspect of the workshops were that they had gained a great deal of useful information. This is interesting, given that the workshop facilitators specifically did *not* provide any information. All the information discussed at the workshops was provided by workshop participants. This suggests that what people in this community lacked was not so much information, as the chance to share and consolidate the fragments of information that were available to them, and to translate these into ways in which made sense to them.

Thus, from our perspective, what people gained from the workshop was not so much information per se, as the <u>social space</u> to process it and to take ownership of it. For many participants, the workshop was the first opportunity they had had to discuss AIDS-related issues in a supportive group setting. Discussion tended to be animated, punctuated by laughter or heated outbursts in raised voices, with enthusiastic discussions continuing throughout the breaks.

People spoke openly. In the context of the silence and stigma surrounding AIDS, some participants showed great courage in speaking openly about family members – often teenage children – who had died of HIV/AIDS. The groups were also successful in exposing participants to an unstructured and democratic discussion format, many of them for the first time. Thus for example, in line with local custom, most groups started off with male and female participants automatically seating themselves in gender-separate groups. In one of their few directive gestures, the workshop facilitators challenged this convention, rearranging the seating so that discussions would be held in mixed groups. Also contrary to local custom, young people were encouraged to express their views on an equal footing with adults. In many cases people accepted this intervention, and discussions often flowed between groups who would not have traditionally shared ideas on an equal footing.

However, there were also some limitations in our efforts to build open and democratic social spaces, with the limitations reflecting existing power inequalities. With exceptions, the most motivated workshop participants tended to be young people and women, who were keen to learn and to discuss obstacles to effective local responses, and ways in which these might be addressed. On the other hand, men often showed great resistance – often bordering on downright refusal – to participate in workshop discussions. Significantly, this refusal was the most marked in the traditional healer group and the traditional leader group. Whilst there was interest in the project amongst a few leaders, other male participants in the leaders group simply refused to engage in any form of discussion at all, insisting that they had nothing to discuss, and that they had come to listen to report-back from the researchers and not to participate in discussions.

In relation to HIV-prevention, male denial of risk is a central challenge. Furthermore, the participation of traditional healers and traditional leaders would be central to any attempts to facilitate more effective community responses to HIV/AIDS. In some ways, the pattern of workshop participation reflected wider resistances to any form of social change from the most powerful local groups (men, leaders, healers). These are the groups who have the most to gain from the hierarchical power relations and undemocratic forms of social interaction which drive the HIV/AIDS epidemic, and which stand in the way of the types of social changes that would enable more effective HIV/AIDS management (the empowerment of women and youth, a more open and democratic public sphere and so on).

To what extent did the workshops facilitate a sense of ownership of the challenge of HIV/AIDS management by participants? In workshop discussions, people *did* start to openly acknowledge the extent of the problem in the community and the fact that they were personally vulnerable. However, there was consensus amongst participants that given a lack of basic skills, and given the stigmatised nature of HIV/AIDS, it was unlikely that community members would lead an accelerated response to HIV/AIDS in the absence of an ‘external change agent’ of some sort. This point is taken up below.

To what extent did the workshops increase participant confidence in the existence of local strengths and resources – both individual and collective - to respond to HIV/AIDS? The workshops definitely served to increase peoples’ recognition of the value of the volunteer community health workers, of their need for further support from the community. To a certain extent the group discussions got some people thinking about possible assistance they could offer the volunteers, as well as people with AIDS and their caregivers at the individual level. These included forms of support such as prayer, showing love and compassion, visiting people with AIDS and helping caregivers with housework and home chores. However, aside from individual strategies, discussion of more collective efforts tended to vague and general – such as comments about the need for the community to join together to fight HIV/AIDS, and of the need for volunteers and community leaders to work more closely together. However these discussions tended to be abstract, and lacking in any real action agenda.

In addition to disseminating findings to the nine groups of local community residents, a tenth workshop was held with potential partners from outside the community – including government service providers (linked to hospitals, clinics and welfare departments in the wider region), the regional municipality (the local level of government to which some economic and political power is delegated by national government), a missionary, representatives from a counselling NGO, and a provincial commercial sector representative. At this workshop it was apparent that although the area officially fell under the ‘area of responsibility’ of all the workshop participants, few had any knowledge of its existence and virtually none of them had ever been there. As such, the workshop played a vital role in bringing the existence of this remote community to their attention, as well as giving Entabeni residents the opportunity to present and discuss the needs and challenges of the community. The workshop was a great success, with most participants expressing enthusiasm for the idea of working in partnership with local community members – describing this as an exciting ‘alternative’ strategy for service provision (all of them having been trained in more conventional ‘top-down’ service provision strategies). Every workshop participant expressed an interest in attending a follow up meeting to brainstorm possible strategies for forming and operating a ‘multi-stakeholder partnership committee’.

Participants’ views of the way forward

In all the dissemination workshops, there was general agreement that the volunteer health workers were best placed to lead a programme seeking to promote greater local ownership of the challenge of HIV/AIDS management, and greater awareness of the role that community-level responses can make in addressing the challenge. In follow-up discussions between the volunteers and researchers, it was decided that they would do this through activities such as creating opportunities for confidential discussions amongst different peer groups about the impact of HIV/AIDS in their own lives and possible responses; through training a wider range of community members in HIV-prevention and AIDS-care skills; through networking both inside and outside of the community to create support networks for people living with HIV/AIDS and their caregivers; and to improve the community’s ability to access distant and hard-to-reach health and welfare services that may be available.

The volunteers welcomed the possibility of expanding their role, on condition that appropriate training and support was available to them for this role. They too were unanimous that without the input of an ‘external change agent’ to provide an impetus for accelerated action it was unlikely that local people would have the confidence to overcome stigma and initiate more intensive community-led efforts to support the volunteers. Community residents have invited the HIVAN team (the authors of this paper) to take on this role in partnership with local community representatives over a three-year period. They were generally very positive about our possible input. We are able and willing to do take on this role, subject to being able to raise funding for our involvement. At the time of writing, we have secured funding for the first year of the proposed project (July 05-July 06), and are seeking funding for two years thereafter.

Implications of workshops for the way forward: aims and objectives of the intervention

Against this background, our partnership with this community has recently started, in the interests of pursuing three key goals. Our first goal is to facilitate local volunteer health workers' access to the skills *they* say they need to improve their effectiveness: home-based care, counselling, peer education, skills to train other community members in basic care and prevention techniques; and networking. The latter includes learning how to help people access welfare grants, and how to build support networks both within and, where possible, outside of the community.

Our second goal is to facilitate the creation of social environments most likely to support local volunteers' efforts. This challenge will include leadership training programs, with specific focus on developing the skills and confidence of local traditional and religious leaders to mobilise support for volunteer health workers and their efforts, as well as promoting the development of leadership by women and young people, currently under-represented in local decision-making. It will also include networking and building of partnerships between local people and outside support agencies to sustain the project on a long-term basis. Our third goal is to facilitate the development of an on-going volunteer-implemented training programme whereby skills relating to health, social development (including agricultural skills) and leadership can be disseminated more widely throughout the community.

The issue of sustainability is at the heart of the HIVAN team's motivations. We define our role very clearly as that of external change agent - working with a marginalized community to develop the skills, capacities and networks necessary for fighting for, and working towards, the development of social environments that enable and support the possibility of improved health. We will not be providing any of the services or training ourselves, all of which will be provided by collaboration between grassroots people and external partners. This is not to undermine the significance of HIVAN's role. Without our energy, confidence, expertise and advanced networking skills this project would not have happened. A number of efforts will be made to ensure sustainability once we withdraw. These will include not only working to build vital capacity and networks within and between local and external partners, but also to motivate for the currently informal project structure to become institutionalised within four permanent institutional structures (within the departments of health and welfare, the local municipality and the local branch of a national counselling NGO).

They will also include the challenge of ensuring that project facilitation responsibilities are written into the formal job descriptions of particular employees in each structure. All these organisations are over-burdened and under-resourced, so this challenge is a strong one. The issue of sustainability is discussed in more detail below.

Phase Three: Facilitating ‘AIDS-competence’ – preliminary activities

In the five months since we have started to implement project activities (which we started at the end of the dissemination process in March 2005) we have already made some progress in three activities, each of which are briefly outlined below. We outline these activities in the interests of illustrating the way in which we are using our six-point model of AIDS-competence to inform and evaluate the on-going progress of the project.

Preliminary skills training for volunteers

Working with volunteer worker representatives, the HIVAN team has facilitated the first phase of building volunteers’ skills through putting the community in touch with a faith-based organisation (located in a large city 2.5 hours drive away) which offers two-week workshops in ‘Home nursing for AIDS-care’ skills. This organisation sent a senior nursing sister to run two workshops in Entabeni, attended by a total of 70 volunteers. The course focused on a wide range of skills and topics around basic HIV/AIDS education, home nursing skills, counselling and obtaining grants. A month after the course, the organisation organised a Graduation Ceremony, at which volunteers were presented with certificates and where each of them publicly took the ‘Volunteer Health Worker’s Pledge’ to use the knowledge they had gained in service of the community. With volunteers in white blouses and black skirts, under black university-style graduation gowns and mortar boards, this was a formal ceremony, attended by local dignitaries, including local community leaders and other senior members of the community, as well as friends and families of the graduates. Despite their very extreme poverty, the graduates raised money to buy gifts for the trainer and for the two HIVAN team members who had helped to set up and run the training course. They also raised money for food served after the ceremony.

It would be impossible to adequately describe the eloquence of the speakers, the singing, dancing and jubilation that attended the graduation ceremony and the party held thereafter, or the pride and joy expressed by the volunteers in evaluation interviews conducted a month after the graduation (8 weeks after the course). Throughout the experience, people repeatedly referred to the training as the culmination of their ‘dreams’ – dreams of receiving formal training in practical skills (beyond the reach of most uneducated women in a remote and isolated community), dreams of receiving public recognition of the hard work that many of them had been doing without thanks or payment for several years. The training had also led to new dreams: the dream that they would one day be able to use these skills and certificates as the route to gaining formal paid employment of some kind, and the dream that other community members might one day receive the empowerment that they themselves had achieved through the training.

This training contributed positively to our overall task of promoting each of the six components of AIDS-competence. In terms of knowledge and skills the benefits to the volunteers were immense. Thus for example, many of them who had been nursing dying AIDS patients for years, had never been aware that it was possible to bathe a patient in bed. The work of some had been hampered by unnecessary fears, through not knowing the extent to which HIV/AIDS could be transmitted through casual contact. People repeatedly referred to the value of the counselling training, saying that this had given them skills and confidence that had considerably lightened the emotional burdens of working with dying people in the 2 months since the course. They also referred to the importance of the factual knowledge they had gained, saying that this had given them confidence in answering questions asked by patients and their families, and also by young people, desperate for knowledge about HIV/AIDS in a context where their peers were dying, who, as a result of the publicity given to the training course, now felt more confident to approach the volunteers with questions.

The high profile course had opened up *social spaces* for discussion about HIV/AIDS – not only with young people, but also with patients feeling the confidence to ask questions that the volunteers too felt confident to answer. The volunteers commented that their new-found confidence coupled with the social status of being course graduates meant that they had increasingly felt able to raise the topic of AIDS in discussions as they went about their everyday lives – and had done so frequently whilst working in communal gardens, for example, or talking to relatives. Volunteers repeatedly spoke of the way in which the course had added to their sense of personal motivation, confidence and credibility. They said that the training had increased the respect they were shown by the community and by traditional leaders, and raised levels of recognition of the value of their efforts. The strategy of according the traditional leaders a key role in the graduation festivities had increased their willingness to support the volunteers efforts – and had also resulted in these leaders spreading information about the volunteers and their efforts in their constituencies. Thus, it had served to increase the leaders' sense of *ownership* of the problem of HIV/AIDS and responsibility for supporting the volunteers in their work. Volunteers agreed that such support was vital if they were to upscale the work they were doing, and raise the profile of HIV/AIDS in the community in as positive a manner as possible. Volunteers accounts of the increased levels of trust and support they were receiving from fellow residents were evidence that the training had contributed to a sense of *solidarity* amongst grassroots residents, as was the increased support from leaders.

Our evaluation of the training course was conducted only two months after the course, and one month after the graduation, in the full-flush of the enthusiasm that will often follow any high profile event in any community. Clearly the challenge remains to sustain this enthusiasm and this positive energy and support after the memories of the ceremony have faded. In the HIV/AIDS world in South Africa, there is increasing scepticism about the long-term value of one-off training courses in poor communities, in the absence of on-going long-term support for trainees. Over the next year, the Project will hold monthly voluntary workshops, run by a nurse from outside the community, in which trainees will be able to discuss any problems or challenges they are facing in applying the knowledge they acquired on the course. The Project will also establish a weekly drop-in service for trainees, staffed initially by an outside nurse, but eventually by an experienced local volunteer who will receive further training to provide such support. In time we also hope to train a cohort of local volunteer trainers to disseminate skills very much more widely throughout the community.

We have no doubt that many challenges will face the optimal success of this initiative. Two were immediately apparent even at this early stage, and link to the challenges already highlighted in the research dissemination workshops above. The first challenge relates to the general unwillingness of men to acknowledge the problem of HIV/AIDS, support the volunteer health workers and participate in project activities. Reference to the need to involve more men – both at the grassroots level and amongst traditional leaders – in AIDS work was repeatedly made in the graduation speeches. The second was to do with the absence of the community's senior traditional chief, Chief Xulu[5], from the graduation event. The attendance of many local leaders from the leadership level immediately below that of the traditional chief was a huge achievement, and showed a great deal of progress given the patchy participation of such leaders in the dissemination workshops as discussed above. However in the long run, for the optimal success of the program, the public support of the supreme local chief would be a great advantage given that he holds ultimate authority in the community. His open support for the programme would be the most effective way of reaching sceptical men and conservative traditionalists for example.

The chief was invited to this event by the volunteer leader, and accepted the invitation. But as had been the case in previous Project-related events where his attendance was expected, he did not attend. Both his mobile phones were switched off when people tried to ring him and remind him about the event. He is an extremely busy man, with an almost overwhelming set of responsibilities. Furthermore he has always been fully supportive of the researchers and the Project from a distance, allowing them to move freely around in the community, and responding positively to one-to-one reports of project progress from the volunteer leader. However he has yet to give it his public endorsement. In the context of the stigma surrounding HIV/AIDS, and feelings of total powerlessness in the face of the complexity of the epidemic, leaders have often been slow to take a public position on HIV/AIDS. Mobilising the chief's public endorsement is a key and vital challenge facing project participants.

Building partnerships

We have outlined the way in which the volunteer training served to increase five preconditions for AIDS competence: knowledge, social spaces, ownership, confidence in local strengths and a sense of local solidarity. The sixth precondition in our model is that of supportive bridging relationships between community and outside agencies. A key assumption of our work is that marginalized communities cannot be expected to single-handedly solve problems without significant support from outside agencies that have the political and/or economic resources to assist them in achieving project goals. A key achievement of the project to date has been the

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[5] A pseudonym to protect the anonymity of the community.

progress it has made in building partnerships between local community representatives and previously unconnected outside actors and agencies.

As discussed above, our case study research included interviews with a range of representatives of relevant public sector, private sector and civil society groups in the region – all within the radius of one hour's drive from Entabeni. In research interviews, few of these groups were even aware of the community's existence. All of them expressed a sense of helplessness in relation to the ravages of the epidemic in the more remote rural areas - coupled with a desire to do something useful, if someone would only take the initiative to link them up to 'hard-to-reach' communities, and to help them identify what to do. Against this background there has been a sense of strong enthusiasm, with every single group representative expressing an interest in being part of a 'partnership' to support it.

Extensive efforts have been made to feed research findings back to this group, and to keep alive the interest expressed in the interviews, and at the time of writing the HIVAN team are facilitating the development of the Xulu Partnership Committee[6]. The aim of this committee is to provide support for local volunteer health workers in running an upscaled community-led HIV/AIDS management programme. Mindful of how busy people are, and of a general atmosphere of 'meeting fatigue' amongst people working in an economically challenged region where so much social development work remains to be done, the whole group is to meet quarterly, with more frequent small working group meetings to discuss particular specialist tasks.

The Xulu committee includes representatives of various sectors of the Entabeni community, HIVAN, the single local missionary-led community based organisation, the nearest municipality (local government) office, the nearest government primary health care clinic, the two nearest hospitals that have an HIV/AIDS clinic, the local branch of a national counselling charity, the nearest clinic that provides voluntary counselling and testing and support groups for HIV positive people, the welfare department who control access to grants and representatives of a philanthropic foundation funded by the regional Chamber of Commerce.

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[6] 'Xulu' (a pseudonym) is the name of the area's traditional chief. Local project participants emphasised the importance of acknowledging his stamp of approval if the project was to have any hope of success amongst grassroots people.

To date these partnership meetings have been highly successful, yielding offers of various forms of support. An example of a particularly successful collaborative effort has been the establishment of a project-run drop-in centre in Entabeni that will serve as a support & advisory office (on issues such as counselling, condom distribution, accessing welfare grants) and a training centre (training, mentoring and supporting trainees in skills relating to HIV/AIDS, agricultural skills and leadership). Initially this centre will be staffed by employees of the counselling charity. However the express aim of these external health workers will be to train local people to completely take over the service after a period of one year.

The building for the drop-in centre already existed in the community (a simple four room structure with no electricity, left behind by a road construction company) has been made available to the project by a local traditional leader, who facilitated meetings of the HIVAN team, the counselling charity, and relevant local leaders to negotiate the function and staffing of the centre. Support of local leaders is essential not just as protocol, but also given their ‘make or break’ power in any local activities.

Even in a four-month period, representation in the Xulu partnership committee has given grassroots Entabeni representatives vital skills in planning and chairing meetings, mobilising local peoples’ support, giving formal presentations, and co-ordinating the forthcoming Youth Rally discussed below. Local community members have repeatedly spoken of the way in which participation in these activities has boosted their levels of confidence and made them realise individual and community-level strengths that they were not aware of. They have also valued the opportunities that they have had to network with organisations and individuals with whom they previously ‘would have only dreamed of meeting.’

However, despite these successes, there have also been some disappointments. Not all the partners have acted to provide the support they promised in the case study interviews. Thus for example the commercial sector representative who enthusiastically pointed to various potential ways her agency could support the project at the research interview stage, quit her post soon after. Her replacement expressed some surprise at our requests for support – saying that as a commerce-funded philanthropic agency she certainly didn’t have the funding to deliver on the expectations her predecessor had raised.

The participation of some government representatives has been disappointing. The public sector, particularly in more remote areas, is bogged down with transformational changes (associated with the challenges of constructing a new post-apartheid administration), lack of resources, heavy workloads, low salaries and limited skills (especially in relation to growing pressure to move away from top-down service provision to social development approaches). Public servants are also bogged down by the sheer number of social regeneration projects that are expected to contribute to in such a challenging social environment. In addition, several individual public servants have said that whilst they might be personally motivated to help us, their freedom to participate in non-standard activities (such as our partnership) is dramatically constrained by rigid hierarchies and red tape. Much work remains to be done in undermining the historical culture of 'top down' government, which limits civil servants' ability to participate meaningfully in the less predictable progress of 'bottom up' projects which seek to accommodate local needs.

These are some of the many challenges that face the project in its goal of building bridging relationships with potential support agencies outside the community. However, to date there have been as many triumphs as disappointments, and a general acceptance that it is best to focus energy on consolidating links with those partners who have come forward to participate, and to simply accept the absence of the others. Furthermore, whilst it may not always be possible to elicit the active support of all the potential partners in proactively participating in project activities, we hope that we will still be able to pull in less proactive partners around specific short-term tasks on a case by case basis. Thus, for example, whilst the head of the regional welfare department has not arrived at partnership meetings as hoped, it is still hoped that she will respond positively to a request to train volunteer health workers in how to assist local people in accessing welfare grants from her department.

Campbell (2003) highlights a number characteristics of an effective 'external partner' in the context of community-led HIV/AIDS management. These include commitment, capacity, incentives, accountability to project beneficiaries, organisational infrastructure to link partners. Given our experience to date, what is the outlook for each of these? The extent to which project partners will deliver on their initially enthusiastic *commitment* remains to be seen. We are guardedly optimistic that a significant number will, even if others do not. In terms of *capacity*, several potential partners do not have social development expertise, having been trained in more traditional one-to-one service delivery methods. However they are keen to acquire new skills and see the project as a channel for doing this. In terms of *incentives*, the notion of grassroots participation is enshrined in the South African constitution, and national government policy requires government agencies to build local peoples' capacity to make a meaningful contribution to tackling the health, welfare and social development challenges that face them from day to day. Thus there is strong policy pressure on civil servants to develop new skills and models for these activities (although somewhat ironically, as already discussed, the structure and culture of government departments often works to hinder them from doing so). Much work remains to be done in thinking through channels through which the project can be held *accountable* to beneficiaries (the residents of Entabeni). Finally, as discussed above, the HIVAN team has taken on the task of constructing organisational infrastructure to support the partnership in its early stages. But it is hoped that the currently informal project committee will eventually develop into a self-sustaining formal programme – which institutionalises 'joined up working' both amongst external partners, and between external partners and the Entabeni community.

Youth rally

We have no doubt about the success of the skills training and partnership exercises to date. The third project activity which the Project is currently working on is a Youth Rally. Whilst this event also shows evidence of promoting some dimensions of AIDS competence in some ways, this activity more than any other has highlighted the complexities and challenges involved in work of this nature, as well as some of the ambiguities of the concept of 'AIDS-competence' which will be discussed below.

The idea for a 'Youth Rally' arose as a result of local peoples' concern that young people are still being infected with HIV/AIDS in large numbers, despite the fact that they witness the AIDS-deaths of their peers on an almost daily basis. This has resulted in the establishment of a local committee, which, at the time of writing, is planning the event, aiming for an attendance of 1000 young people. Activities will include musical bands and dancing, a talent contest, a drama seeking to facilitate AIDS-awareness and motivational speeches from people living with HIV/AIDS.

The HIVAN team is represented on this 10-person planning group, along with the local religious missionary, two local leaders, two school-age people, three volunteer health workers and a local teacher. Our initial comment was to see only the two school-aged people as ‘youth’, and to comment on ‘youth’ under-representation on this body. However, local leaders pointed out that both the health workers and the teacher were aged between 25 and 35, and as such were considered ‘youth’ in the community.

Being involved in organising such a large and complex event has been a steep learning curve for virtually all the committee members, with fast and effective experiential learning about planning, networking with outside organisations (including a radio station and the drama group) and collaborating with community representatives of various ages, experiences and perceptions. However this process is also fraught with complexities. Adult men on the committee were unanimous that the aim of the day should be to promote sexual abstinence by young people. Whilst we are very strongly in favour of sexual abstinence as an HIV-prevention strategy for those who are likely to adopt it, our view would have been that given the reality of high levels of youth sexual activity, it would be beneficial to offer young people a range of options for avoiding HIV: abstinence, monogamy or condoms. In our research study in this community, young people repeatedly told us that ‘abstinence messages’ had no resonance with the reality of their own lives and norms, and that they perceived them as irrelevant and meaningless.

We expressed this view in the committee – emphasising that our view was supported by our research findings. However in line with our commitment to a project that is community-led and community-owned, we had to stand down when it became evident that no other committee members were willing to openly support our view. Our involvement in the Youth Rally reflects some of the complexities of outside agents working with local people to further community-led programmes, where the values of community representatives are at variance with their own.

Our sense of complexity is exacerbated given that our view is fuelled by a great deal of research evidence, including interviews and focus groups with the very types of young people targeted by this rally. It is also exacerbated by our private perception that young people are not adequately represented on the committee, so that the so-called ‘community representatives’ are not indeed ‘representative’ of the relevant constituency. This point is taken up in the conclusion of this paper.

Suffice to say at this point that it could be argued that – in some ways – this extremely well-intended Youth Rally might have unintended consequences which work against the concept of AIDS competence outlined above. Some might argue that the rally will be promoting a form of *knowledge* which we already know that the target audience might not want or be able to translate into action plans in their own personal lives. The value of the '*social space'* provided by the rally might be undermined as a result of it feeding irrelevant or partial knowledge to young people, undermining the possibility of open and democratic discussion, leading them to make personally relevant decisions about a range of behavioural possibilities. The conservative and adult-formulated abstinence message might potentially decrease rather than increase a sense of youth *ownership* of the problem, alienating young people rather than developing actionable understandings of it, and increasing their sense of AIDS denial, or of helplessness in the face of AIDS, by presenting them with an action message that does not make sense to them. This would obviously have negative consequences in terms of drawing young people into networks of local *solidarity* around HIV-prevention, and so on.

Systems change and sustainability?

How does our work relate to the 'systems change' focus of this special edition of the *AJCP*? As discussed in the introduction to this paper, we interpret the term 'systems' to refer to those formal and informal community networks and relationships that support and sustain the on-going promotion of the psycho-social processes of knowledge and skills, safe social spaces, ownership and responsibility, and an appreciation of local strengths.

We see our role as working to build sustainable systems that support more effective community-led HIV/AIDS management at two levels – both within and outside of the community. Firstly we will seek to facilitate the development of systems *within* the Entabeni community through working with local residents to establish HIV/AIDS management skills, project management and leadership skills, and sustainable administrative/leadership structures to support this work over the long term. A key focus of Project activities will be to develop formal procedures to ensure that these skills are widely disseminated to local people (including women, men and young people), through training and supporting a cadre of local volunteer trainers over time using a 'cascade system' of training. We will also seek to institutionalise the dissemination and deployment of these skills within the community through finding permanent homes for project activities within existing buildings, and through working hard to mobilise a cohort of supportive leaders – with the goal of establishing project support and sustainability as one of their formal responsibilities. These might include traditional leaders where possible, as well as leaders of already established church, women's and youth groups.

The second level at which we will seek to build effective systems over time is through strengthening and formalising the links between the Entabeni community and *outside* support agencies, including local government and other potential project partners. This will be done in two ways. Firstly through working to build the capacity of local government departments (especially health, welfare and the municipality) to be more responsive to community needs. This will include working with local government agencies to develop the skills needed to tailor their services to accommodate community needs and to mobilise and support appropriate community participation in providing local HIV/AIDS management services. Here, the HIVAN team will use its advocacy role to motivate for the development of local government capacity and systems that are geared towards social development approaches to health (rather than one-to-one service provision which has historically been the approach favoured by local government health and welfare departments). Secondly efforts will be made to institutionalise local government and NGO support of the programme. As discussed above, this will be done through working to ensure that the activities and responsibilities involved in Project participation become part of the official duties of the four established local government and NGO structures outlined above (health, welfare, municipality and a local counselling NGO), with these duties being written into the official job descriptions of particular post-holders in these established structures.

Conclusion

In this paper we have presented our evolving conceptualisation of AIDS competence, and illustrated how we are using this concept to guide and evaluate our participation in a community-led HIV/AIDS management project. We have done so in the interests of contributing to debates about how to facilitate the development of social environments that support members of marginalized communities to make optimal use of health services where they exist, and to cope in situations where health services are inaccessible or inappropriate for their needs.

We have sought to show how this conceptualisation has guided us in our on-going work in Entabeni without blinding us to two types of complexities. Firstly there are the complexities of facilitating community responses to HIV/AIDS in a community whose indigenous norms and views of the solutions to HIV/AIDS may often be different to ours. Secondly there are the complexities of seeking to address – through local community mobilisation - problems some of whose origins often lie in extra-community factors (e.g. poverty, gender, age hierarchies) over which community members may have little control.

As stated above, the aims of the project are to support community health workers in leading an accelerated community response to HIV/AIDS; and to create a supportive social environment through building partnerships with outside agencies, and promoting various health, leadership and social development skills amongst local people, as well as amongst external partners. In this process as the HIVAN team we have seen our role as that of *external change agents* - working with Entabeni residents to develop the skills and capacities necessary to build social environments that enable and support the possibility of improved health.

Our initial case study highlighted the tremendously unsupportive context in which the beleaguered volunteers were struggling. Against this background, the project has made very encouraging progress in the first five months of its existence, generating much energy and goodwill, and many positive responses from many local people and grassroots partners. These responses suggest that even in this apparently unpromising context, many of the preconditions for AIDS competence were already present in this community – albeit in a latent and untapped form – and that the community's engagement with the HIVAN team has served as a useful catalyst for identifying and mobilising these.

Clearly there is still a long way to go, and many hurdles to cross. A key challenge facing the HIVAN team is the stressful and time-consuming process of raising funding to cover our salaries and operating costs from one year to the next. To date, our experience suggests that the role of an external change agent with the necessary contacts, power and confidence to organise initial training courses and build strategically important networks and partnerships can be very positively instrumental in enabling local people to tap the local strengths and resources needed. The key role that the HIVAN team has played in catalysing this process raises all the usual questions about the replicability of this project in other areas who do not have a 'HIVAN team' to work with over a number of years until project activities are institutionalised in formal community and agency structures as described above. We do not have answers to these questions, other than to say that our experience suggests that without our presence this project would not have happened. Perhaps the most we can say here is that it is a myth to regard the mobilisation of grassroots community participation as a cheap way of delivering services and addressing social problems in deprived communities, and that those seeking to implement such approaches need to recognise that they are extremely resource intensive to initiate and sustain.

Within the community health and psychology literature, there is often a strong emphasis on the need for grassroots community projects to serve as building blocks for wider forms of political activism that explicitly challenge the power inequalities and social injustices that underpin the marginalisation of so many communities. In relation to idealised academic discussions of the potential role of community psychologists in facilitating wider social transformation (Campbell and Murray, 2004), how big and how significant should we expect the results of project efforts to be? University colleagues are always quick to point out that many of the problems facing communities such as Entabeni are rooted in power inequalities which are unlikely to be removed in the short term. They would prefer us to define our project's goals in relation to the challenges of eliminating gender and age inequalities and uprooting poverty, for example. In this regard we make four concluding points.

Firstly we argue that the challenges of uprooting poverty and other forms of social inequalities are long-term ones, as opposed to the very immediate challenges facing those who seek to offer help to people dying of AIDS and their families. Much can be done with them, even with the relatively modest resources available to deprived and remote communities.

Our second response is to quote Bulhan, who says that 'power is never conceded without a demand' (cited in Seedat, 2001). Large-scale changes in the social hierarchies that fuel the spread of HIV and the suffering of people with AIDS are unlikely to occur in the absence of forceful demands from below. In this regard, we see our role as one of contributing in a very small way to the long-term challenge of building youth and women's and poor peoples' capacity to articulate their needs and interests. This could be seen as the first step on the much longer path through which highly marginalized groups eventually come to articulate and assert their needs and interests in relation to more powerful groups. Here we are inspired by the maxim of

Archbishop Desmond Tutu, South Africa's Nobel Peace Prize Winner: "How do you eat an elephant? One bite at a time."

This takes us to our third point, namely that people too often define problems in a way that overwhelms their ability to do anything about them (Wieck, 1984). Arguing for a strategy of incremental 'small wins', Wieck would support us in outlining the aim of our project as that of 'facilitating local responses to HIV/AIDS in Entabeni', rather than as that of 'bringing about fundamental shifts in the power inequalities and social injustices that shape South African society'. He suggests that it is important to define problems in ways that do not preclude action, and which recognise the importance of recognising small-scale process as part and parcel of long-term social change.

Finally, Wieck's argument resonates with our view that it is vital to frame project goals in ways that make sense to project participants, and in ways that are achievable in concrete ways that participants understand and identify with. Elsewhere we have written of the HIVAN team's unsuccessful attempts to engage Entabeni women in discussion about the possibility of challenging male domination in their personal lives (Campbell, Nair and Maimane, 2006). In all our Entabeni research, gender inequalities repeatedly emerged as key drivers of the epidemic, with community members strongly endorsing these findings in research dissemination exercises. Yet the notion of openly challenging men made little sense to women, who saw gender inequalities as an issue to 'work around' rather than tackle directly in its own right – and who preferred to advocate a much more immediate set of project goals that related very directly to their practical day to day struggles with HIV/AIDS. We believe that it is important for outside participants in community projects to respect such views. Projects are far more likely to succeed when goals are formulated by, and make sense to, community residents than by outsiders seeking to impose abstract theories of social and political change on people whose priorities and concerns are far more immediate.

Within this context, we believe that the challenge facing the project is to identify goals that are specific, realisable and immediate. We believe that small gains have the potential to incrementally develop peoples' skills, knowledge, ownership, mastery and confidence to gradually take on more challenging goals. The challenge is that of identifying relatively quick, tangible first steps (e.g. facilitating local responses to AIDS) only modestly related to grander political outcomes (e.g. promoting fundamental social transformation through toppling power hierarchies). First steps need to be driven by actions that can be built on, actions that signal commitment and competence for the next stages (Alinsky, 1984). In this project we take our lead from the volunteers – and the working style they have developed over the past years – seeing hope in almost impossible situations, and being prepared to work long and hard for small gains. The process has begun. The challenge is now to develop and sustain it.

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