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**Supporting people with AIDS and their carers in rural South Africa:
possibilities and challenges.**

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1. Introduction

HIV/AIDS is currently the chief cause of death and illness in sub-Saharan Africa. Rural areas, where people may often have limited or no access to health and welfare services, carry a significant weight of the sub-continent's overall HIV/AIDS burden (Barnett and Whiteside, 2004). In South Africa, the focus of this paper, about half of the population lives in rural areas. We present a case study of community¹ responses to HIV/AIDS in a deep rural community in KwaZulu-Natal province. We do so to further understandings of (i) how social environments support or hinder the coping abilities of people with AIDS and their carers in rural areas, and (ii) how grassroots community strengths and resources might best be supported. Our research was the first step of an on-going project involving the collaboration of the authors and residents of Entabeni, where 43% of pregnant women are HIV positive, and where people have limited access to formal health or welfare support, and HIV/AIDS is heavily stigmatised. The long-term aim of this collaborative project is to promote the development of social environments that are more supportive of local community responses to HIV/AIDS management.

Elsewhere we have conceptualised three aspects of the social environment that impact on the ability of communities to respond effectively to the challenges of HIV/AIDS (Campbell et al., 2005). These are the *material context* (poverty, unemployment, hunger), the *symbolic context* (stigma, gender relations, and conflicts between traditional and biomedical health services) and the *networking/institutional*

¹ Communities are most commonly defined either as people who share a common identity, or as people who live and/or work in a common geographical space. In practice health promotion interventions usually target their efforts at geographically defined communities. It is this place-based notion of community that is used in this paper.

context. The latter dimension refers to the extent to which public sector, private sector and civil society networks are supportive of people with AIDS, and the quality of the collaboration amongst these networks to enhance the cumulative effect of their individual efforts to promote effective AIDS-management. Whilst much research has been conducted on the material and symbolic dimensions of context, far less has been conducted on the networking/institutional context. It is the latter dimension that forms the focus of this paper.

To date, the main response to HIV/AIDS in Entabeni has been informal home-based care by local women. Home-based care plays a vital role in the care of millions of AIDS patients in sub-Saharan Africa. Studies have highlighted the negative impacts of the burden of care (Campbell and Foulis, 2004). These include burnout (Lindsey et al., 2003), impaired physical health (Akintola, 2006), emotional distress (Kipp et al., 2006), family breakdown (Nnko et al., 2001; Thomas, 2006) and the destruction of household economies (Rugalema, 2000). Peoples' abilities to cope are undermined by poverty (Orner, 2006; Uys, 2002), stigma (Campbell et al, 2004; Russell and Schneider, 2000; Thomas, 2006), lack of social support (Orner, 2006) and the social exclusion of women (Akintola, 2006) and youth (Robson, 2006). However less is known about how people cope with these burdens, particularly in relation to:

- the formal and informal community networks available to assist people with AIDS and their carers; and
- the factors shaping the effectiveness of these networks.

Such information is needed to inform community strengthening policies and interventions to enhance support for carers and patients to minimise strain and hardship.

An appreciation of the role of supportive social environments in facilitating care lies behind the growing interest in how to facilitate 'health enabling community contexts'

viz: contexts which enable and support effective responses to AIDS by local people. In international HIV/AIDS discourse, it is universally accepted that the strategies of 'community mobilisation' and 'partnerships' have a key role to play here. This acceptance is partly the result of the disappointing outcomes of so many HIV/AIDS prevention programmes imposed on poor communities by outside experts (Gregson et al., 2007). Such programmes have sometimes even eroded local coping mechanisms through failing to understand and work with local networks (Gruber and Caffrey, 2003). Well-intended short-term development programmes – implemented by northern professionals flying in and out of poor countries for short periods – can undermine local capacity to mount effective and sustainable HIV/AIDS management responses in African settings (Pfeiffer, 2003).

Reference is often made to the need to ground responses to HIV/AIDS within local community networks. Robson (2000) speaks of the need to strengthen local networks to support carers, and Thomas (2006, p.3186) emphasises the need for "locally appropriate initiatives" to support carers and challenge stigma. In addition as Wangila, Wafula and Mukhwana (2002) argue there is a need to build alliances between development agencies and donors and these local networks of home-based carers and community organisations. This needs to include strong links between formal and informal health care systems to allow more effective treatment of illnesses (Harding and Higginson, 2005). While Uys (2001) speaks of the need to establish a good network of informed partners to support local carers. Partners, such as government, missionaries and NGOs, all need to be mobilised to achieve effective support (Ntsutebu, Walley, Mataka and Simon, 2001). However, whilst the importance of strengthening local networks that support and enable effective AIDS-care is repeatedly emphasised in a general way at the level of recommendation and rhetoric, little is known about the types of networks that actually exist in AIDS-affected communities that might form the basis of such efforts.

Ogden *et al.* (2006) criticise international policies on home-based care (e.g. WHO, 2002) for focusing very narrowly on the health care needs of patients. They argue for the development of more holistic approaches, which take account of local networks available to support carers and their families. Our research seeks to fill this gap.

Our starting point is that each community has its own unique way of responding to AIDS. Building 'AIDS-competent communities' does not necessarily involve importing solutions, conceptualised and managed by outside experts, but rather *facilitating the most promising local responses*. This involves a shift from the concept of 'intervention' to the concept of 'facilitation'. However whilst this insight makes theoretical and political sense, much work remains to be done in translating it into action in real social settings. We present our case study to promote understandings of which features of social context support or undermine effective responses to AIDS, as well as discussing how such facilitation might take place.

2. Research methods

Case study of a rural community

To investigate factors most likely to facilitate or hinder mobilisation of existing and latent community resources, the authors conducted an in-depth case study of community responses to AIDS in the tribal authority of Entabeni², a deep rural community of around 50 000 people in KwaZulu-Natal.

Our study was conducted in partnership with the area's traditional chief (*Inkosi*) and local community health volunteers. The *Inkosi* gave his approval to the study, and

² This is a pseudonym, in line with ethical commitments to the confidentiality and anonymity of our informants.

mandated the leader of the health volunteers to introduce us to the community and help us identify informants. We conducted 45 in-depth interviews and 13 focus groups (including 55 participants) with a range of local residents (including people living with HIV/AIDS, their carers, health volunteers, local leaders, young people, men and women) as well as representatives of local private and public sector groups with an interest in HIV/AIDS management in the wider geographical area. Detailed fieldworker diaries contextualised the interviews.

In justifying our choice of the case study method, we distinguish between two forms of research. Hypothesis-testing research is conducted when researchers know what they are looking for, and are able to define and measure their variables of interest prior to the study. Hypothesis-generating research is preferred when researchers are working in an under-explored area, and don't know best how to define their variables of interest (in this case aspects of the social environment that might facilitate or hinder the care of people with AIDS). The goal of such research is to describe the case in as much detail as possible, in the interests of mapping out areas for future research (Bromley, 1986).

The extent to which case study findings can be generalised to other contexts is a controversial one (see Cornish, 2004, for a discussion of this). Some argue that it is not possible to generalise findings, and that the applicability of findings from one case to another is a matter of empirical investigation. Others argue that generalisability is possible, with decisions about generalisability dependent on the expert 'human judgement' of experienced social researchers (Flyvberg, 2001). Yet 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. We concur with Cornish (2004, p100) who argues that "a case study enables us to investigate how a

particular policy, which might sound impressive at an abstract level, actually plays out in its instantiation on the ground, in practice". In this paper, our policies of interest are those that highlight the role of network building in the challenge of facilitating local community responses to AIDS.

Topic guide and analysis

An open-ended topic guide examined the context of informal AIDS care through eliciting peoples' views of the national political context; local community life; the efficacy of local leadership; the causes of HIV/AIDS; its impact on the community; the role of different groups in HIV/AIDS management (formal and informal civil society, public sector, private sector); and the potential for grassroots mobilisation and multi-stakeholder partnerships to facilitate indigenous responses to HIV/AIDS.

These interviews have generated an extremely large data-set. Using interpretative thematic analysis (Flick, 1992) this paper seeks to identify key AIDS-relevant local actors and agencies from civil society, the public sector and the private sector and the way in which they have responded to AIDS, and factors facilitating or hindering their response.

3. Findings

Entabeni is an isolated rural area, 30km from the nearest town or health facilities. Residents have limited or non-existent access to basic health and welfare services, clean water and roads. There is high unemployment (Stats SA, 2007), high illiteracy amongst the adult population, and dependence on subsistence farming for survival (Aliber, 2001). The area covers a vast geographical space, but is very hilly and subject to regular droughts, which makes farming difficult.

The area is governed by a traditional chief (the *Inkosi*), a strong and charismatic figure, widely revered and obeyed. For various reasons, related to competing commitments, he spends a lot of time elsewhere, delegating everyday matters to 20 or so area-based traditional councillors or *Induna*'s. However their power is limited, and defined as subordinate to his. The majority have little formal education or leadership training of any sort. Beyond the formal leadership, the power structures in the community are strongly patriarchal. (Mathais, 2007; Williams, 2004)

Poverty is rife, levels of illiteracy are high and TB, AIDS and cholera are common (Barron et al, 2006). At least one in four adults are believed to have HIV/AIDS, and informants spoke of death as a common occurrence in the community, especially deaths of young people. The only HIV/AIDS statistics available for this community suggest that 43% of pregnant women are HIV-positive (HEARD, 2005). Polygamy is widely practiced. Furthermore, many employed men are migrant workers who travel and engage in multiple sexual relationships, with women having little power to protect their health in sexual encounters with migrant partners (Lurie et al, 2003). The absence of migrant partners leaves a high number of female-headed households. Residents have little or no access to radio, television or any sources of information about HIV/AIDS or how to avoid it (Shisana et al, 2005). Most also have limited opportunities to get out of this isolated place, given lack of roads, poverty and the limited and unaffordable nature of local transport.

Care of the sick is usually done by informal care givers (mostly family members) because of the lack of health facilities in the area, the great distances that people have to travel for medical assistance (Tanser et al, 2001), and the very limited number of health volunteers available to offer home-based care in such a large and

hilly area, where a volunteer may have to walk up steep hills in the blazing heat to homesteads located up to an hour's walk from each other.

3.1 Needs of patients and carers

Interviews pointed to multiple needs of AIDS patients and their carers. At the material level, people spoke of shortages of money, food and affordable transport to clinics or hospitals. Few informants knew anything about government plans to roll-out antiretroviral treatment to people with CD4 cell counts of less than 200. Hospital workers expressed reservations about the ability of residents of such a poor and remote community to access and adhere to drug treatments once they were available. In other words, HIV/AIDS was an almost certain death sentence for most affected. Many households had no income at all. At the practical level, people battled without many of the basic resources for home nursing, such as gloves, bedding or clean accessible water. The burden of care was often the final straw for already over-extended women. Many carers were also sick themselves. At the emotional level patients and carers felt isolated in a community where stigma made people reluctant to disclose their HIV status, often even to their carers. This meant that both patients and carers often battled on with no emotional support. Fear of disclosure also limited peoples' access to what little care or support might be available. Having said this, within the parameters of the stigma and secrecy around AIDS, both patients and carers were often active and resourceful. But their frantic attempts to cope were continually foiled in unsupportive social environments which presented very limited opportunities for help.

3.2 Support available to patients and carers

Having looked at some of the challenges facing people with AIDS and their carers, we now turn to look at the formal and informal networks available to assist them, as well as factors shaping the effectiveness of these networks.

3.2.1 Civil society

When speaking of civil society, we refer to the range of informal and formal networks and organisations – unrelated to government or private sector – that play a role in HIV/AIDS management. The first of these were **informal networks of families and neighbours**. Immediate families – parents, siblings, children and grandmothers - appeared to carry nearly all the burden of care of AIDS patients. As already stated, their burden was often aggravated by the secrecy many families sought to maintain about the status of the family member they were caring for, which led to their alienation from potential help from neighbours, friends or health volunteers (where the latter existed). Whilst there were stories of rejection and abandonment of some AIDS patients by their families, there were as many stories of acts of compassion, care and sacrifice towards family members with AIDS. This was also the case in relation to neighbours. There were many stories of brutal gossip and rejection. But there were, however, many stories of neighbours sharing their own scarce food with AIDS-affected households, or with poverty-stricken, grandmother-headed or child-headed households.

What of **local voluntary associations**? The social capital literature cites voluntary organisations as a key community resource (Saegert et al., 2001). People who belong to well-functioning local organisations are more likely to protect their sexual health (Gregson et al, 2004; Campbell et al, 2002). The presence of voluntary organisations in a local community is also regarded as beneficial to non-member residents through offering the potential for health-enhancing support in a range of

indirect ways (Kawachi et al, 1997; Martin et al, 2004). Our interviews yielded only a few references to sewing, gardening or soccer groups, but these were small and isolated single-issue groups. The only organisation which seemed to have any real presence or network infrastructure in Entabeni was the networks of various churches. These tended to hold regular Sunday meetings and week-time prayer meetings, and church members visited the homes of sick people to pray. However it was clear that local churches had not come to terms with the complex challenge of HIV/AIDS. No church had any activities which openly or explicitly addressed HIV/AIDS. It was clear that churches took a punitive approach to HIV/AIDS, regarding it as the result of 'bad sexual behaviour'. People said that discussion of HIV/AIDS was explicitly discouraged in local churches.

In our interviews with the local chief (*Inkos*), he pointed to **traditional healers** as the key local resource in the fight against AIDS because of their degree of influence, and their accessibility. The community was home to large numbers of traditional healers, who were an easy health resource for local people, both in terms of their geographical accessibility (compared to the relatively hard-to-access medical health clinics and services), and also because they often allowed patients to pay on credit. Local traditional healers tended to work in competition rather than co-operatively, fiercely guarding their methods and remedies from each other. Some, but not all, claimed to cure AIDS. Many diagnosed HIV/AIDS as the result of the bewitching of the patient by their enemies. This provided a convenient smokescreen for those in denial about their HIV status in the climate of stigma and fear. People with AIDS often relied on traditional healers until they were very sick, only accessing biomedical care and treatment in the final stages of their illness.

The most important community resource were the **volunteer health workers**, who played a central role in facilitating the informal home-based care of people with AIDS

They were the only group, besides family members, that offered direct care and support to AIDS patients. Nearly all of them were unemployed women. They visited households and provided basic health education (e.g. personal and household hygiene, water purification), as well as general home-based care and support for 'sick people', including many AIDS patients, although patients seldom admitted the nature of their illness to the volunteer health workers.

There were two types of volunteer health workers: those that offered less skilled help (e.g. collecting wood or water, or cooking). And others, which had rudimentary nursing skills and training in DOTS (directly observed therapy for tuberculosis patients). They had acquired these skills through the unsystematic and often temporary inputs of religious missionaries, NGOs and patchy government interventions. The latter group were more likely to work hand in hand with clinics and hospitals. Few volunteer health workers had basic literacy, none had any kind of HIV/AIDS knowledge or training, and they worked without any kind of payment or even stipend to cover their expenses. Their work involved walking long distances on foot, often up steep hills, and often in conditions of searing heat, to households which might be several kilometres apart.

This group was co-ordinated by a local man on the *Inkosi's* council who the volunteers had elected to be their leader. He alone received a small stipend from a provincial NGO that provided minimal support for AIDS-care throughout the province. Unlike the other volunteer health workers, he was educated and relatively worldly (having worked in an administrative job in a big city for 20 years before returning to his community of origin). He was highly respected by the group, an inspirational leader. However he had limited political power, and whilst the role of the volunteer health workers was formally recognised in the community, they receive little real support from the *Inkosi* or his councillors.

Stigma often meant that after long walks to households rumoured to be housing seriously ill AIDS patients, volunteer health workers would be turned away by families denying that this was the case. Working outside of the context of supportive health and welfare systems, with little recognition from local leaders or the church (the only established informal network in the community), dealing with the severest and most challenging of health problems in a climate of hunger, poverty and often hopelessness, this group was remarkable for their dedication and commitment, and their willingness to work incredibly hard for the smallest of gains.

The **Entabeni Community Programme** was spearheaded by a dynamic older woman – an independent missionary from Western Europe, who had raised a small grant to live in the community for two years, in simple conditions without comforts or amenities. She had set up various projects from an old Mission building in Entabeni, including a crèche, community gardens and craft projects. She also provided a minimal stipend for a few volunteer health workers. Her work had been slow paced, ensuring that the local community felt ownership of the projects she had initiated.

She was characterised by a particular talent for seeing possibilities for change and growth within what others might regard as impossibly difficult situations. She strove to turn these insights into action - with infinite patience. Her modus operandi was to set herself and her project small and achievable aims, and to see the value in modest achievements – on the basis of visions that were consistent with what members of this community were able to do. Thus for example, she spoke of the great efforts she had made to get three local men trained in carpentry, so that they would be able to do essential building work to house her project activities.

The *Inkosi* or traditional chief was the supreme power in the community. Little happened in the community without his support and blessing. His position in relation to HIV/AIDS was a complex one. He identified it as a key problem and actively encouraged and supported our research project. In some respects he had a deep insight into the nature of the problems facing his subjects.

However he had yet to work through ways of transferring this concern into action in his community. This was partly due to the rigid nature of traditional power structures (e.g. the strict protocol around approaching him) which made it difficult for grassroots community members to access him. As a result he was very distant from his subjects. Furthermore, despite speaking of the need for the empowerment of women and youth, the reality of his old-fashioned views on sex and his authoritarian attitude to the youth and women, were out of kilter with the more egalitarian underpinnings of state-of-the-art HIV/AIDS management techniques. In short he knew that HIV/AIDS was a problem – but had little understanding of how it manifested in his community. He also had little understanding of the complexities of HIV/AIDS management, but was aware of these shortcomings and open to the possibility that the researchers might be able to provide advice and expertise in this regard.

As stated above, his leadership style involved delegating power to a cadre of **traditional leaders** (the *Izinduna*). However aside from their key role in resolving daily disputes and conflicts amongst residents, this group had little autonomy. Their role involved carrying out the *Inkos*'s orders, and looking to him for advice on how to handle any unexpected situations – whilst having limited access to him on a day by day basis. The *Izinduna* had little HIV/AIDS-related knowledge, and had made no contribution to any form of local response to HIV/AIDS. Volunteer health workers cited the *Izinduna*'s lack of recognition of their role and efforts as a key obstacle to their work. In a focus group discussion, some *Izinduna* candidly expressed the view

that they were in urgent need of leadership training, not only in relation to facilitating a response to HIV/AIDS, but also in relation to dealing with the daily demands of their work, where they often felt unqualified to carry out their roles.

3.2.2 Public sector

In Entabeni, health and welfare support was very basic, with many gaps in service provision and grant access. From the service user perspective many of our informants spoke of inadequate services and incompetent or unsympathetic local government employees. From the service provider perspective, public sector workers told us that they were expected to work under incredibly difficult conditions, in under-resourced settings, and often without appropriate training. They spoke of the absence of a culture of constructive criticism, skills-building and positive career development. People feared making creative suggestions to improve their working practices, lest they appear more competent and knowledgeable than their supervisors – which would not be tolerated in a strictly hierarchical context.

The **Department of Health** offered a mobile clinic service which made monthly visits to the area. People complained endlessly about the need for more frequent clinic visits. They said the mobile clinics offered very basic services, with few or no drugs, and was only staffed by nurses. Whilst there were large general hospitals in each of four surrounding towns, on average 30km away, the costs of transport to these centres was unaffordable to most people. Even if they managed to transport themselves to hospital, chronically ill patients were often treated and then sent home immediately rather than being admitted, due to bed shortages. A range of other difficulties impaired health service provision. These included the refusal of the ambulance services to enter some parts of Entabeni due to their fear that ambulances might be hijacked or that ambulance staff would be victims of crime.

Patients living in these 'no go' areas would have to be carried in wheelbarrows or on peoples' backs, to meet ambulances in safer parts of the community. Chronically over-burdened hospitals were chaotic, under-staffed and with high staff turnover, with many prospective patients battling to find their way around them.

Despite this, there were some exceptional doctors and nurses. These had high levels of dedication and sophisticated understandings of the social dimensions of AIDS, and of the limitations of what help they could offer in the face of the complex needs of AIDS patients. Thus, for example, the superintendent of a large hospital spoke of how his hospital's ability to offer adequate services to AIDS patients was severely limited by lack of knowledge about local community support networks. They also lacked crucial insights into the types of support available for patients in ensuring continuity of medical treatment, monitoring of medication, appropriate home care and so on. He spoke of the urgent need for the development of channels to mediate between health services, patients and community support structures such as volunteer health workers.

The local **Municipal Authorities** had a dedicated HIV/AIDS co-ordinator, charged with improving HIV/AIDS management in the municipality's large geographical area, which included our tribal authority of interest. He said that a few years previously, he had made some attempts to build networks of agencies and communities to improve HIV/AIDS management. However these had been unsuccessful. He had ambitious and insightful plans for future network building efforts, but said that he would have to wait for funding to implement these. He had devoted a great deal of time to the necessary fund-raising, and had been awarded a large grant from an overseas humanitarian agency. However, he faced many delays in accessing this money, which was being funnelled through central government.

The **Department of Education** were responsible for promoting HIV-awareness in schools. Interviews with officials in the local high school suggested that local schools' responses to HIV/AIDS had been minimal. There had been a number of one-off HIV-awareness talks – sponsored by a local business – in school assemblies. The school's 'Life Orientation Curriculum' did have a small HIV/AIDS awareness component in Years 8 and 9, which was functioning. However, the teacher who had attended the Education Department's obligatory HIV training course as the local high school representative had since died and had not been replaced.

Amazingly, in interviews and focus groups, the school principal and teachers said that they did not regard HIV-awareness activities as a high priority. They said that neither school learners, nor other community members, were at high risk of HIV. They described the community as an intensely conservative one, steeped in traditional cultural restrictions around sexuality. In sharp contrast to this, in interviews and focus groups with schoolboys and schoolgirls, learners spoke openly about having unprotected sex in a way that suggested how out of touch the principal and teachers were with the realities of their pupils' lives. Young people said how urgently they needed access to more information about HIV/AIDS, in relation to both HIV-prevention and AIDS-care, given that many had family members living with AIDS. They also stressed their need for opportunities to work through some of their confusions and uncertainties about the HIV/AIDS information that had filtered through to them through various sources.

3.2.3 Private sector

Reference has already been made to occasional one-off HIV-awareness efforts made by local businesses in the area. Aside from this, there was no private sector involvement in our community. There was one extremely successful private sector

hospice located some distance away from Entabeni. This was too far away from our area of interest to offer any help, and it tended to prioritise patients with access to private medical aids. However we mention it (i) because its an example of an astoundingly successful venture by the private sector; and (ii) because we know that this organisation is keen to develop links in the hard-to-access deep rural areas of the kind we are working in – as part of their social responsibility agenda. As such, they could become a very effective partner in any future attempts to set up partnerships to facilitate community responses to HIV/AIDS in Entabeni.

This private sector hospice was established by an NGO set up by **a coalition of local businesses**, which had established a centre dealing with all aspects of HIV-prevention and AIDS-care. This was an extremely successful self-funded venture, run by a dynamic team led by a high powered business-woman with an international post-graduate qualification in running non-profit businesses. Run on business principles, the NGO engaged in a range of fund-raising activities. The centre had also raised funds from a range of local and international businesses and donor agencies. Furthermore, they had consulted widely and successfully with groupings ranging from government bodies to local civic leaders. A key determinant of their success was that they had done all the work and fund-raising themselves, and had not expected any very active participation from their local government and civil society ‘partners’. However, this initiative served as an excellent illustration of the potential of the private sector to contribute to local HIV/AIDS management where there is political will on the part of local businesses, and one dynamic individual – with high level business skills – to drive forward fund-raising as well as project implementation and management.

A second ‘top-down’ initiative run by a dynamic individual was spearheaded by another missionary from outside of the community. Driven by a religious vision, she

had come to this area and set up a thriving centre including an **AIDS hospice and orphan assistance project**. Here again, the project was located some distance from our research community, but we mention it as an example of the sterling work that can be done by private individuals in remote areas. This was very much a 'one woman show', resting heavily on the fame and energy of a single person. She had raised all her own funding from local and overseas businesses and donors. She expressed the view that funding for local AIDS projects was freely available to those who are prepared to work for it. Her work had frequently been showcased in the international media, where she was something of a celebrity. She was a controversial figure, which she ascribed to her status as a powerful and well-funded individual person in a resource-poor region. She said she had received poor support from local clerics, and was a victim of false and malicious gossip, with many enemies.

4. Implications for facilitating local responses to HIV/AIDS?

What are the possibilities of facilitating more effective local community responses to HIV/AIDS? We have spoken of the dominant research and policy rhetoric about the need to promote community participation and partnerships for HIV/AIDS management. What are the possibilities of converting this rhetoric into reality? The comments below are based on the authors' analysis of our research findings *prior to* an extensive period of community consultation which we will shortly engage in – subject to getting funding for a project in which we hope to work with Entabeni residents to convert our research findings into action.

Since our role in such a project would be defined strictly as one of external change agent working with local people to develop community-led and community-owned grassroots action, the final shape of such efforts would have to be negotiated with

local people at great length through the research dissemination workshops we have planned.

What factors stand in the way of optimally effective coping by people dying of AIDS and their carers? What would constitute the features of an 'AIDS competent community context' that a community development programme might seek to promote? Based on our findings of what currently constitute obstacles to effective coping in Entabeni, 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.

We believe that such a community context might best be facilitated through facilitating a formal partnership involving all the groups outlined above. In the absence of formal support from actors and agencies outside of the community, it is unlikely that members of such a marginalized community will get any further than they have to date in responding to HIV/AIDS. Furthermore, the HIV/AIDS problem in Entabeni is too multi-faceted and complex to be tackled by any single constituency. Such a programme would ideally be led by the *Inkosi*, given his tremendous power. Such a programme would initially target schools (youth and parents), churches, traditional healers, health volunteers and traditional leaders. We would suggest starting with these groups because they are the easiest to reach. A key challenge facing the partnership would be that of targeting youth out of school. Initial project activities would take the form of (i) knowledge and skills-building for HIV-prevention and AIDS-care; (ii) working to develop group facilitation skills based on dialogue and

critical thinking; and (iii) training skills amongst targeted groups to enable them to train other community members in a 'cascade system'; and (iv) basic training in literacy, leadership and small-scale agricultural skills.

We would advocate Freire's (1970, 1973) approach, which sees dialogue and critical thinking as a necessary precondition for collective action to strengthen communities. This is because we believe that it is only through debate and dialogue that people are likely to develop an understanding of the obstacles standing in the way of improved HIV-prevention and AIDS-care – which would form the basis for collectively constructing a vision of a social environment where people worked together to tackle such obstacles.

At the start of this paper we emphasised our commitment to interventions that seek to facilitate existing responses rather than intervening from the outside. This politically and theoretically sound point disguises immense complexity, given that some of the community's strengths and resources are at the same time the very forces which have undermined an effective local response to HIV/AIDS. We highlight some of these complexities here.

The *Inkosi* has been very supportive of our research, and is keen for us to become more involved in HIV/AIDS management work in the local community in the future. This is a tremendously positive starting point. A project would not survive in this community without his support. Yet in many ways, it is the very autocratic and hierarchical leadership style that characterises deep rural areas – and in which the *Inkosi* is embedded – that often serves to disable initiative or independent action by grassroots people in any areas of life, let alone ones as complex as HIV/AIDS. Furthermore, whilst the *Inkosi* himself is a highly educated person with advanced

leadership skills, many of his *Izinduna* are less well educated and lack the skills to promote effective community development.

In this patriarchal social setting, women and youth – who carry the heaviest burden of AIDS care, and have the least power to protect their sexual health – are definitely second class citizens. They lack the confidence, skills and social recognition to assert themselves in the community at large. However in private interviews, the *Inkosi* he spoke with sincerity of the way in which women were the backbone of the community. He also referred to the need to change gender attitudes and to empower women and youth as part of the struggle against HIV/AIDS. Furthermore, implicit in his support for our research, and in his invitation to us to facilitate an HIV/AIDS management intervention, is his acknowledgement that something more needs to be done about this problem, which is an important opening for a potential project.

In relation to faith-based organisations, there is a thriving network of churches in Entabeni, potentially a key network for a project seeking to improve peoples' prospects for health and well-being. However, the church's teachings on sex, and its shame and blame attitude have contributed to the AIDS stigma and denial that thrives in this community. Why then target the churches as key project participants? At the pragmatic level, they are the biggest and best established social network in the area. However at a more subtle level, whilst our interviews have portrayed the church as strongly distancing itself from any involvement in anything to do with HIV/AIDS, there was evidence that some church ministers and many church-goers and their families have been personally affected by AIDS. A range of constraints prevent the churches from openly tackling the issue themselves. Yet we believe, despite this, that there might be a receptive constituency within the churches, were they to be included as partners in a community-wide initiative, initially given impetus and support through an external change agent. Furthermore at least one church minister in Entabeni has

a very explicit commitment to the social development of youth, part of which he believes is empowering them to protect their sexual health.

In a network-poor community, schools are clearly a key resource for accessing learners and their parents. The teachers and parents we spoke with seemed not to regard HIV/AIDS as a problem in what they described as a traditional and conservative community in which young people tended to be 'well-behaved'. Despite this, our findings suggested that learners were desperate for more opportunities to learn about HIV/AIDS and to discuss issues around sexuality and sexual health, but lacked facilitators to provide such opportunities. Here, efforts to use the schools as a network for skills-building and dialogue around HIV/AIDS would benefit greatly if the *Inkosi* could be persuaded to mobilise school principals to enable such work. Potential project participants would need to work to convince the *Inkosi* of the value of using schools as networks for HIV/AIDS work.

The *Inkosi* has identified traditional healers as a group he would particularly like any future HIV/AIDS programme to work with. Traditional healers play a key role in HIV/AIDS management in partnership with medical doctors in some parts of Sub-Saharan Africa (e.g. Peltzer, et al, 2006; Wreford, 2005). However in this isolated rural community, much of their appeal lies in their claim that western doctors have failed people in relation to HIV/AIDS, and that they have the ability to cure AIDS through their own methods. The extent to which this group could be mobilised to participate in HIV/AIDS awareness and skills-building remains to be seen. Here again we would have to rely on the authority of the *Inkosi* to do the initial mobilisation of this group and see if this generated any sustainable interest or energy amongst the traditional healers themselves.

The health volunteers are definitely the most vital resource in relation to HIV/AIDS management. In our view, they are the most promising group to lead community-led efforts to facilitate more effective local responses to HIV/AIDS. A key theme that repeatedly emerged in our interviews with this group was the way their work was hampered by illiteracy and lack of basic HIV/AIDS related skills and knowledge. This is an area that a proposed project might fruitfully take as its starting point.

How much could be done by a small-scale community-led intervention in such a deprived and network-poor community? As researchers, we believe that we have a potential contribution to make in supporting this work, and we have access to the types of funding bodies who might support our involvement. In discussions of research ethics, there is growing reference to the need for researchers to ensure that their findings feed into actionable efforts to improve the lives of their research informants. What added value could we bring? Firstly we would provide an impetus for action, which many informants told us was lacking. There was a strong recognition that 'something more should be done', but a generalised reluctance to initiate this. Secondly we have access to a body of skills and experiences about social development strategies, knowledge which our informants said was sadly lacking. Thirdly we now have a huge amount of information about this community. Research informants from every sector said that they looked forward to hearing our findings, and that in various ways they lacked information about 'what was going on in the community'. Finally we have networking skills and resource to facilitate links between the community and extra-local actors and agencies that might have the resources to assist a project in meeting its goals.

With significant start-up support from an outside change agent, and the establishment of a formal partnership structure pulling together representatives of the groups referred to above, we feel cautiously optimistic about the possibility of

improving local AIDS competence. As laid out convincingly above, the obstacles to effective action in such a multi-challenged community are great. However we believe that a potential project could do worse than to take inspiration from the indigenous style of small-scale activism that is already established in this community, particularly by the health volunteers and the Western European missionary. This involves starting very small, devising modest goals which can be achieved with existing local capacity – and most of all seeing hope in highly challenging situations.

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