

**Andrew Gibbs, [Catherine Campbell](#) and Sbongile Maimane**  
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# Can local communities 'sustain' HIV/AIDS programmes? A South African example

Andrew Gibbs (HEARD, Durban), Catherine Campbell (LSE), Sbongile Maimane (HEARD, Durban)

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**Abstract:** Globally there is renewed interest in building local sustainability of HIV/AIDS programmes to ensure that once funders withdraw, local communities can sustain programmes. While the 'local sustainability assumption' is widespread little research has assessed this. In this paper we assess the sustainability of the Entabeni Project, a community-based intervention that sought to build women's local leadership and capacity to respond to HIV/AIDS through a group of volunteer carers, three-years after external support was withdrawn. Overall the sustainability of the Entabeni Project was limited. The wider social and political context undermined volunteer carers' sense that they could affect change, with little external support for them from government and NGOs, who struggled to engage with local community organisations. At the community level, some church leaders and community members recognised the important role of health volunteers, many continued to devalue the work of the carers, especially once there was no external organisation to support and validate their work. Within the health volunteer group, despite extensive efforts to change dynamics, it remained dominated by a local male leader who denied others active participation while lacking the skills to meaningfully lead the project. Our case-study suggests the local-sustainability assumption is wishful thinking. Small-scale local projects are unlikely to be able to challenge the broader social and political dynamics hindering their sustainability without meaningful external support.

## **Introduction**

HIV/AIDS remains a major global health burden, particularly in southern Africa where an estimated 60% of all those living with HIV/AIDS live (UNAIDS 2012). From the earliest responses, there has been a strong push to ensure local engagement, participation and ownership. And while there have been unprecedented funding flows to southern Africa, a range of factors including the global economic crisis, the increasing cost of ART programmes and declines in donor funding for HIV/AIDS, have led to increased emphasis on the sustainability of interventions. As such, there is renewed interest in building locally sustainable programmes (UNAIDS 2012).

This paper seeks to promote debate about the sustainability of health programmes by local communities. This ideal is frequently aimed for in development programmes, and HIV/AIDS-related community mobilisation in marginalised settings, but seldom achieved in practice (Farmer 2005). International NGOs often fund programmes in low and middle income settings, aiming to 'empower' communities to respond more effectively to the challenges of HIV prevention, care, treatment access/ adherence or impact mitigation (Cornish, Priego-Hernandez et al. 2014). Such community mobilisation programmes often start-off as 'partnerships' between communities and external NGOs. They often put extensive effort into training marginalised groups to increase their knowledge and skills related to HIV, as well as build confidence to take control of their sexual health. Alongside this, training is provided to build leadership and management skills, assuming following this the international NGO will withdraw and the community will be able to sustain the programme.

Despite the wide-spread nature of what we call the 'local sustainability assumption' within HIV/AIDS management programmes and the millions of dollars spent on such programmes, little formal research has assessed the extent to which local communities are able to sustain efforts, once external support is withdrawn. However, beyond the offices of international NGOs, substantial informal evidence speaks of HIV/AIDS projects collapsing when outside funding, supervision and support is withdrawn. Such anecdotes echo the large literature in development studies, which has long documented community failures to sustain externally initiated projects (Kumar and Corbridge 2007). In a now classic paper citing widespread evidence of community failure to sustain externally initiated development processes, Cadribo refers to Africa as a "graveyard of development projects" (Cadribo 1994 p22).

## **Rationale for community mobilisation**

Community mobilisation, a pillar of international HIV/AIDS policy and intervention, is considered vital for three reasons according to Campbell and Cornish (2010). First, to translate externally conceived HIV/AIDS management approaches into locally appropriate discourses and practices. People's experiences of, and responses to, HIV/AIDS are embedded in local worldviews and survival strategies that have a poor fit with the biomedical and behavioural frames of reference that dominate globally conceived programmes. Second, community mobilisation is deemed necessary for building local capacity to 'sustain' externally funded programmes once funding is withdrawn. Such participation of local people is also central to the 'task shifting' agenda emphasised in global responses to health (WHO 2008). Third, relates to the social-psychology of health-related behaviour change, namely that people are most likely to behave in ways that optimise effective HIV/AIDS management if they live in social environments that enable and support health-enhancing behaviour (Tawil, Annette et al. 1995).

Against this background, the concept of the 'HIV-competent community' highlights six psycho-social features of communities where people are most likely to collaborate with one another, and outside support agencies, to develop effective local responses to the challenges of prevention, care, treatment and impact mitigation

(Campbell, Nair et al. 2007; Nhamo, Campbell et al. 2010). These are HIV-relevant knowledge and skills, social spaces for dialogue and critical thinking, a sense of ownership and responsibility for contributing to tackling the effects of the epidemic alongside professionals, recognition of individual and group strengths to do so, local solidarity and partnerships with supportive external agencies in the public and NGO sectors.

### **The Entabeni Project: 2003 – 2008**

The 'local sustainability assumption' was at the heart of the Entabeni Project which was widely analysed and reported on by Campbell and colleagues (Campbell, Gibbs et al. 2008; Nair and Campbell 2008; Gibbs, Campbell et al. 2010; Gibbs, Campbell et al. 2014). The Project ran for five years (2003-2008). Entabeni is a remote and impoverished rural community in KwaZulu-Natal, South Africa, where 36% of pregnant women were living with HIV (Campbell, Nair et al. 2007). One of the few resources in the community was volunteer carers, who are at the heart of the HIV/AIDS response in sub-Saharan Africa (Wringe, Cataldo et al. 2010). The Entabeni Project can be understood as a three phase project, led by an NGO called HIVAN, linked to a local university.

#### ***Phase 1: Baseline (2003)***

In 2003, HIVAN undertook a study exploring local responses to HIV in Entabeni. This emphasised the vital role played by unpaid volunteers in caring for terminally ill patients with little access to formal health support, in homesteads without running water or electricity (Campbell, Nair et al. 2007). Caregivers' work was undermined by their lack of training, stipend or recognition from other community members in a context of HIV stigma and denial.

#### ***Phase 2: Dissemination as intervention (2004)***

In 2004, Campbell and colleagues used their 'dissemination as intervention' methodology to report-back research findings to community groups. This methodology encouraged participants to brainstorm how they could use the research findings to develop strategies to improve their wellbeing (Campbell, Nair et al. 2012). The outcome of this process resulted in HIVAN being invited to set up a community-led programme to build the ability of the health volunteers to lead a strengthened local community response to HIV/AIDS.

#### ***Phase 3: Entabeni Project (2005-2008)***

In 2004 funding was raised from a large US donor and HIVAN took on the role of ECA, in a project with three goals: i) build local community HIV/AIDS competence through expanding the skills of the volunteers to facilitate local responses to HIV prevention and care, ii) strengthen local community support for their work, and iii) establish a permanent partnership committee including community members and representatives of external agencies (Campbell, Nair et al. 2007; Nair and Campbell 2008). At the end of the three year funded period HIVAN would withdraw and the programme would continue under the management of the partnership committee.

The Entabeni Project has been extensively documented elsewhere (Campbell, Gibbs et al. 2009; Gibbs and Campbell 2010). According to their analysis successes included training the existing group of carers to offer radically improved home-based care and support the development of a hospice setup by a lone Scandinavian missionary (Campbell, Gibbs et al. 2008; Gibbs and Campbell 2010). This missionary was a pillar of support to the Project. HIVAN also linked local people to a range of external training and support networks. The Project also successfully mobilised support from some religious leaders who had previously lacked the skills, courage and motivation to openly support people living with AIDS in a context where churches had tended to view HIV/AIDS as a punishment for sinners.

The Entabeni Project, however, faced many challenges. The local traditional chief, while supporting the Project through enabling access to the community, repeatedly stated that condoms would waste the sperm that God had given him. Indirectly his deeply autocratic adult-male-dominated leadership style undermined project goals to empower youth and women (Campbell 2010; Gibbs, Campbell et al. 2010). The traditional chief appointed Mr Z to lead the Project. Mr Z refused to transfer leadership to the women who ran it, as had been originally agreed. Throughout the Project, the women volunteers remained terrified of him, and he countered their occasional timid efforts to exert greater control over project leadership with extreme anger (Campbell and Cornish 2010).

Young people and men disengaged, seeing little dignity in unpaid work that the Entabeni Project relied upon. They often belittled the volunteers who were prepared to work 'for nothing' (Gibbs, Campbell et al. 2010). Despite extensive efforts to secure government stipends for volunteers, they were unsuccessful. In an effort to sustain the Project, HIVAN managed to raise short-term 'bridging' stipends from the overseas donor. However these were discontinued at the end of the funded period (Campbell, Gibbs et al. 2009).

There were also extensive challenges faced by the Entabeni Project in establishing a permanent partnership committee with representatives from local health, welfare and municipal structures. While organisations were enthusiastic in principle to participate, agencies were under-staffed and under-funded and many public servants lacked the confidence and skills to work with highly marginalised community members, and others were unwilling to engage with extremely marginalised people as equal (Nair and Campbell 2008).

At the end of 2008, as planned, HIVAN's involvement ended as funding ended. The HIVAN team left the community with cautious hopes that the volunteer work would continue. A core group of CHWs expressed strong commitment to continue, the partnership committee had been meeting every few months albeit with patchy attendance, and Mr Z vowed to continue to pressurise the Department of Health to raise stipends.

### **Entabeni in 2012: the follow-up research**

In 2012 the authors, conducted a follow-up study in the same Entabeni community to assess the long-term 'footprint' the Entabeni Project had left following HIVAN's withdrawal and factors supporting or hindering its sustainability. The team worked with HIVAN to trace key participants in the original work to achieve this. In-depth interviews were conducted with Mr Z the leader of the group, Faith and Gladys – women who had been key volunteers in the HIVAN period and had previously been interviewed for studies. Also 7 focus groups with 52 community members (28 women, and 14 men), including two groups of health volunteers, two groups of out-of-school youth (aged between 18 and 28), and religious leaders and members of a local craft and dance co-operative were conducted. Participants were identified using convenience sampling; a number of these had been involved in the original project as well, although not necessarily interviewed, and their interviews reflect this. While this potentially introduces bias into the study, we seek to provide a broad understanding of context and footprint of the Entabeni Project, rather than any necessarily generalizable findings (Bauer and Gaskell 2000), Ethical approval was granted by the University of KwaZulu-Natal (HSS/1261/011). Interviews were conducted in Zulu, audio-taped, translated and transcribed, and both fieldnotes and interviews were analysed using thematic content analysis (Attride-Stirling 2001). Throughout pseudonyms are used to ensure anonymity and we have changed any potentially identifying features.

The aim was to generate understandings of factors which facilitate or hinder local sustainability of externally funded community mobilisation programmes. The overall emphasis was that despite a small group of volunteer carers continuing to provide basic home-based care, the Entabeni Project, including the partnership committee,

were no longer functioning. The Project's sustainability despite being programmed from the beginning of its work, and following global good practice on building local community mobilisation and engagement, was essentially limited. In this paper we explore the factors that were supportive of the continuation and sustainability of the Entabeni Project and those factors that hindered its long-term sustainability.

## **Results**

The results paint a complex picture of a multiplicity of factors that shaped, and together ultimately undermined, the sustainability of the Entabeni Project following HIVAN's withdrawal from the community (Table 1). They point to a series of factors, which we group at three levels: 1) Wider social and political contexts, 2) Community-level dynamics, and 3) Internal group dynamics. We discuss each of these in turn.

Insert Table 1 about here

### **Wider social and political contexts**

A substantial body of work emphasises how social contexts shape programme outcomes (Gupta, Ogden et al. 2011). Our findings suggest contextual factors created a sense of apathy among the volunteer carers within the Entabeni Project, rather than a confidence in their ability to impact on social problems faced by local residents.

### ***Lack of wider development***

There were high expectations in the post-apartheid decades that democracy would lead to radical change in people's everyday lives and extensive development. This had not happened and Entabeni remained socially isolated with little sense that change was a possibility, leading to an on-going sense of isolation and 'being left behind' amongst residents of Entabeni:

"We really have a problem here. We are not even asking for tarred roads, but good maintenance of the dirt roads we have. That will be enough than what we have right now. Our roads are maintained maybe once a year or never. There are people here who carry dead bodies for over a kilometre to the main road just because the hearse cannot go to their houses." (Church leader, male)

Feeling left behind and disconnected from 'development' meant residents felt apathetic that they could effect change. As Mr Z the Entabeni Project leader commented people had a tendency to just sit back and wait for change, rather than seeking to mobilise it:

Interviewer: How do people cope?

Mr Z (local leader Entabeni Project): there is nothing people can do. They just sit and wait.

For many residents in Entabeni, the lack of wider development was symbolic of their wider inability to shape the future of their lives. As such, encouraging local residents to continue being involved in a project that sought to change their lives was something that did not resonate with their perceptions of the world.

### ***Alienation from state & state processes***

According to Nair and Campbell (2008) a key aim of the Entabeni Project and something the HIVAN ECA sought to achieve was build connections between the Project's cadre of volunteer carers and state agencies that might assist in strengthening local responses to AIDS. These included the Department of Health (DoH) and local Municipality. Over the Project there had been many ambiguous promises from the DoH that the volunteer carers would be formally recognised and given stipends, alongside meaningful support from the DoH (Nair and Campbell 2008). However, following the withdrawal of HIVAN, support from the DoH reduced. Mr Z described

how when HIVAN was involved, the DoH took the carers seriously, but once HIVAN left the DoH ignored their requests for support:

“The DoH didn’t take our calls seriously. After HIVAN withdrew I went to the DoH and one of the officials asked if I was the man who had come with the rude Indian lady [the ECA funded by HIVAN]. So I think when they heard the rude lady had left, they dragged their feet.” (Mr Z, local leader Entabeni Project)

As Mr Z suggested, it was the Project’s association with an outsider who had considerable institutional influence, being linked to a university, as well as tenacity to demand support, that forced the DoH to engage.

Within the DoH there was also a shift towards prioritising support to carers who met strict criteria, in particular a school leaving certificate and accredited training. These requirements effectively excluded nearly all the women who had volunteered and worked tremendously hard on the Entabeni Project while it had been supported by HIVAN, creating despondency amongst the volunteer carers. They felt it was short-sighted of the DoH to prioritise those with an education rather than those who would be most likely to commit to long-term volunteer work:

“I am very disappointed when I heard the Department of Health is only interested in people who have passed matric. All I know is that this person who has a matric will not want to work in the community forever. She has opportunities for better jobs, but I, with a very low education, am completely committed to working with this community because I don’t have other options. Also I have a lot of experience from my years of working with sick people locally, and the skills I have obtained through all the trainings that HIVAN provided. People with more education don’t want to stay in these rural areas.” (Health volunteer, female)

### ***Failure of bridging relationships with NGOs***

NGOs are meant to have a special ability to work with marginalised communities and be responsive to their particular needs and requirements (Wallace and Porter 2013). Over the Project, the external ECA had worked to link NGOs to the carers (Campbell, Gibbs et al. 2009). These NGOs were seen as able to provide training and support for the carers to continue their work once HIVAN exited the community. However, according to informants, these NGOs struggled to do so once HIVAN had left, despite assurances that this would not happen.

One national NGO HIVAN linked to provide on-going support to the hospice the health volunteers had setup and worked at, slowly withdrew its support once HIVAN left. According to Mr Z, the NGO said it was too hard to work with health volunteers in a remote, rural area, with limited access to e-mail and cellphones:

“Mpume withdrew from our project, saying our work was not up to standard. She wanted our filing to be up to standard and she wanted us to communicate with email. We tried to do that, but because there is no network here, it didn’t work. So they withdrew, *saying that since HIVAN had left the community, it was not going to be easy to work with us...*” (Mr Z, leader Entabeni Project, male)

Indeed, the lack of ready access to email and cellphones meant the local leadership of the Entabeni Project struggled to organise meetings with NGOs. They also felt they lacked the influence to secure meetings with other organisations as they lacked the institutional power to do so and were easily side-lined compared to HIVAN:

“If I remember, HIVAN were the ones that used to call them to meetings, send them emails, and phone them. HIVAN had the proper structures and money to do that, but when HIVAN left us we didn’t have these means, and other organisations, Lifeline and the Department of Welfare pulled out because there was no one pressurising them.” (Gladys, member Entabeni Project, female)

The wider social and political context was one in which Entabeni community members had a limited sense of confidence in their ability to effect change because of exclusion from the state, local political dynamics and widespread poverty. Furthermore, external organisations tasked with providing support to local community efforts whether government or NGOs, either did not feel obliged to engage or lacked the tools to meaningfully do so, undermining the sense that the Entabeni Project was seen as an important resource for HIV/AIDS management.

### **Community level factors**

One objective of community mobilisation was to build support for the volunteer carers within Entabeni (Campbell, Gibbs et al. 2008). In numerous papers, Campbell and colleagues argue that carers identified this as a major barrier to their work (Campbell, Nair et al. 2007; Campbell, Gibbs et al. 2009). Since 2008, when HIVAN support ended, informants reported that some of the supportive aspects that had changed through the work of the Project continued supporting sustainability, however many negative aspects continued, undermining sustainability.

#### ***Positive community level outcomes support sustainability***

In some ways, the community remained a space in which there were significant levels of support for the work of the carers, even after HIVAN had withdrawn. Church leaders who had been trained by the Entabeni Project on HIV/AIDS knowledge and skills continued to remain engaged in providing supportive spaces for talking about HIV/AIDS and creating an environment conducive to the carers work:

“I would like to say thank you to HIVAN for all the education they gave us, especially to us religious leaders. HIVAN gave us material to refer to. HIVAN gave us confidence to stand in front of the people and tell them about the virus. Without HIVAN the situation would have been worse by now.” (Church Leader, male)

A major outcome of the Entabeni Project during HIVAN's involvement was increased respect for the carers from many in the community (Campbell, Gibbs et al. 2008). Respect was linked to the carers being seen to provide healthcare in a challenging setting and providing a resource that was typically missing in Entabeni. This respect and recognition of the role the carers played continued after HIVAN's exit and was widely commented upon by carers:

“Members of this community are very fond of us. They welcome us into their households without any reservations. At times, they phone us to come to their homes.” (Health Volunteer, female)

One carer remembered how they used to be rejected by community members and how this had changed:

“What I also like about our community is that CHWs are no longer rejected by the community. They now welcome us to their homes and let us continue with our work. I remember the time when they would ignore us and let us stand for hours on end in the sun. They are happy that we monitor the way they take their medication.” (Health Volunteer, female)

On-going support from some members of the community was critical for enabling carers to feel supported in their work. Much of the support for the carers continued even once HIVAN had withdrawn. This support provided a sense of importance and relevance to the carers.

#### ***Community factors undermine project sustainability***

While many in the community recognised the carers as offering an important service others looked down upon the carers. One carer suggested that the very fact that HIVAN withdrew from the community and the volunteer carers had not been able to sustain the project in any meaningful way, played into a wider community level perception that nothing could ever change or be sustained within the community:

“We were an example even to other communities that we could start a project from the beginning and be able to sustain it for a long time. All that is lost now. The community has also lost hope in us. They are looking at us as people who failed.” (Health Volunteer, female)

Despite carers being valued by some in Entabeni for providing care and support, many also described how they were looked down upon by others for working for free. In their analysis of the Entabeni Project, this had been a significant challenge and had limited the Project's ability to involve younger people and men (Gibbs and Campbell 2010). This devaluation of carers' work was demotivating for carers:

“When we tell other community members that we are still not paid, they accuse us of lying. They say that no sane person could waste so many years of her life doing something that does not bring food home. We leave our families and go out to the community, leaving our families to suffer.” (Health Volunteer, female)

While many people in the community acknowledged the critical role that carers played in providing support and care for people living with HIV in Entabeni, there was a continued sense that in reality the work of the carers, because it was unpaid and done by women was worthless. This undermined the carers' sense that they were making a difference to people. Furthermore, without an external organisation to support the carers, it was perceived that the Entabeni Project was another failed project, one of a litany of failed projects in the community, undermining people's willingness to become involved in it, rather than seeing it as an example of local ownership.

### **Volunteer Carers' Group level factors**

Over the three years HIVAN placed much emphasis on building skills, confidence and processes amongst the group to create a well-functioning and democratic organisation (Gibbs and Campbell 2010). A significant emphasis by HIVAN was the ECA's focus on building a number of younger women's sense of confidence and position them as leadership within the organisation. At the end of the Entabeni Project, the assumption was that these women would remain leaders to enact change and sustain the group (Campbell, Gibbs et al. 2009).

### ***Positive factors internal to group supportive of sustainability***

Despite the overall lack of sustainability of the Entabeni Project, a range of factors internal to the volunteer carer group provided some sense that the work would continue. Many of the factors mentioned were linked to positive experiences volunteers had when they had been supported by HIVAN. Carers emphasised how the support HIVAN had provided through training and skills building had been critical in mobilising them to be able to respond to HIV in the community and that this mobilisation continued even after HIVAN withdrew:

“Before HIVAN came to this community, most of us spent time doing nothing really. We would get up in the morning, go to our fields and after that we would sit around doing nothing worthwhile. With these trainings, we became observant and were able to recognise those things we did not do properly.”  
(Health Volunteer, female)

Some informants described how a small number of women involved in the Entabeni Project had used the training and skills building provided as a springboard for further development and education. Fieldwork notes outline how

one of the young women who had increasingly played a leadership role in the Entabeni Project had used this as a pathway to start a degree and build her confidence:

“Faith is now doing a social work degree by correspondence, and has managed to get a bursary in a context where it’s almost impossible for women over 34 years to get funding. She is now very confident with what she wants to do with her life. She doesn’t take no for an answer.” (Fieldwork notes)

Central to these positive group dynamics was many felt HIVAN had played an open and transparent role in the Entabeni Project, supporting the community and carers to identify what was needed, rather than imposing an externally developed plan:

“We appreciate the fact that HIVAN did not misuse the funds you were given. HIVAN always monitored the funds and how they were used in a way that was transparent to us. HIVAN brought people here, who taught us the skills we needed.” (Health Volunteer, female)

There remained spaces in which the support that HIVAN had provided continued to exerted an influence and sense of potential opportunity. Of particular note was that a number of younger women had leveraged the training provided to move in new directions, previously unavailable to them.

### ***Negative factors internal to group***

Throughout the Project HIVAN had sought to promote more democratic ways of engaging and working (Campbell, Gibbs et al. 2009). Without HIVAN playing this role, the health volunteer group quickly slipped back into ‘traditional’ styles of working that emphasised male dominance and the power of traditional leadership structures. Mr Z, who had been appointed by the traditional chief, continued to control the volunteer carer group and carers were unwilling to talk openly and discuss their problems:

“If you dare to talk to him (Mr Z) about complex issues, you are regarded as a brave person by the other volunteers. It does happen at times that when you put your case, there may be a misunderstanding, and you end up having to answer a lot of questions that you were not prepared for. This is why it is difficult to talk to him. He always thinks when you ask him questions or need to understand something that you are challenging him. Most of us keep quiet for the rest of the meeting because you never know when you are going to be told you are out of line.” (Health Volunteer, female)

This dictatorial style of leadership by Mr Z undermined carers sense of confidence and willingness to continue providing care through a group where they felt so side-lined. Despite Mr Z’s approach to leadership, he struggled to provide a strong and clear leadership and sense of purpose to the group. Many carers expressed that without outside support and guidance the health volunteers lacked the guidance that they needed to be seen to be moving forwards:

“When I asked why there were no new volunteers, they said that a few that joined them soon after HIVAN has left soon lost interest when they saw that the group was not moving forward, and that there was no stipend at the end of the month.” (Fieldwork notes)

According to (Gibbs and Campbell 2010) significant work had gone into building local leadership to take the project forward once HIVAN exited. This involved building leaders’ confidence and sense that they were important. For instance, the ECA had worked with Galdys a younger woman in the community who was seen as a potential leader of the group and it was assumed would take a prominent role in moving the volunteer carers forwards with HIVAN’s exit (Nair and Campbell 2008). Speak to Gladys, she felt that despite gaining confidence, she still lacked the skills and experience to take on such a role:

“HIVAN kept telling us we were important and could do important things. Today I am not afraid to challenge the authorities. What is a pity thought is that since HIVAN left this community we lack guidance. We are still not sure which direction we must take.” (Gladys, member Entabeni Project, female)

The inability of local leadership to set a direction and instil a sense of purpose among the carers was critical in undermining carers’ willingness to continue being involved in the work. One carer described how she became frustrated as the energy disappeared and dropped out of the group:

“I was very active when HIVAN was here because they were my support. When they announced they were leaving I got frustrated and all that energy that I had disappeared.” (Health volunteer, female)

A particular concern among the volunteer carers that undermined the group’s long-term sustainability was the lack of stipends for the work they did. One carer contrasted the sense of purpose and power she felt when she received the stipend for a short-period, to her current position of working only because she loved her community:

“We started this volunteering work in 2003. That is a long time ago when you think we are still not getting paid by the government. We were talking the other day about HIVAN, and how happy we were to go to the bank and draw R200. It was not a lot but it made us happy. Even at home they were happy to see my coming with bags of groceries. It is now very bad. I only continue because I love my community” (Health volunteer, female)

The internal dynamics of the volunteer carers were critical in undermining the long-term sustainability of the project. While HIVAN worked extensively to build democratic approaches, interviewees emphasised how once HIVAN had exited, the group slid back into non-democratic approaches to leadership and leaders lacked an ability to hold the group together. These factors, combined with the lack of stipend, undermined people’s willingness to continue.

### **Discussion/conclusion**

Global, regional and national HIV/AIDS management policies emphasise that communities need to be at the heart of any meaningful response to the HIV and AIDS epidemics (UNAIDS 2012). In this regard the Entabeni Project was an attempt to operationalise global ‘good practice’ around HIV/AIDS management and the local sustainability assumption through strengthening local responses to HIV.

This case study of the long-term impact and sustainability of the Entabeni Project, three years after the original NGO and research team withdrew from the community, suggests that the sustainability of community responses to HIV is a figment of wishful thinking. It suggests that despite a number of positive changes and impacts seen within Entabeni, the overall footprint of the Entabeni Project was limited. Drawing on our data and the previously published analyses of the Project, we identify two major interlinked factors that hindered the sustainability of the Entabeni Project.

The first factor that undermined the sustainability of the Entabeni Project was widespread unequal gender relations within the Project and the wider community. The original intervention and research team identified from 2003 onwards that tackling gender inequalities needed to be central to HIVAN’s work (Campbell, Nair et al. 2007). This included working extensively with the male leader Mr Z on enabling democratic forms of group leadership, and providing substantial support to younger women carers who offered an alternative voice within the group (Campbell, Gibbs et al. 2008; Campbell, Gibbs et al. 2009). Our analysis suggests that without the on-

going support of HIVAN it was easy for Mr Z to 'slide backwards' to his controlling and domineering approach to leadership. Those women that had been supported by HIVAN used their skills and ability to exit the group. More widely in the community, women carers were often positioned in contrasting ways. They were both respected for their work in providing care where none existed, but in being positioned as carers for people living with HIV and as volunteers, they were seen to embody three inter-linked stigmatised and marginalised identities: women, carers and volunteers, a similar finding to Campbell and Cornish (2012). Embodying these stigmatised identities meant the group were never able to meaningfully become actors with social influence in the community, despite being narrowly recognised as 'doing good'. In the future alongside trying to secure sustainable stipends for carers, we suggest that community mobilisation approaches integrate wide-scale community level interventions that challenge gender norms about women's roles, HIV and male involvement in caregiving (e.g. Abramsky, Devries et al. 2012). These potentially create supportive environments in which these social factors are changed, enabling stronger outcomes for small-group processes to build on.

The second factor undermining the sustainability of the Entabeni Project was the failure of external bridging relationships to meaningfully support the organisation. Government and NGOs, despite mandates and commitments to working with community organisations were unable to. There remained an on-going sense amongst these external organisations that they had power and set the agenda, rather than being responsive to local requirements. Indeed our data suggests there was a pervasive sense that local communities were looked down upon unless they were able to come up to the level required by government departments or NGOs, be this in terms of communication or qualifications. This appears to be something that had been recognised by the original team previously and they had worked extensively to try and change this through continually engaging with these organisations and supporting those tasked with these roles to brainstorm round challenges they faced (Nair and Campbell 2008; Campbell, Gibbs et al. 2009). In contrast, the Avahan project, a large-scale community mobilisation intervention in India with sex workers, initially led by NGOs, was successfully transferred over to the control of the Indian state. The analysis of the process of transfer provides both a framework and suggestions on what is required to do this. This includes a much longer timeframe to transfer ownership, modification of processes and structures of working to align more closely to those government and securing high-level political cooperation and support for the work and process (Bennett, Singh et al. 2011). Such processes of transfer are unlikely to be achieved by small community organisations, without the support of an ECA such as HIVAN.

These two factors are interlinked. Throughout the data from our follow-up study when organisations were able to meaningfully support the Entabeni Project – including the HIVAN team - it gave those involved a sense of efficacy to make and effect change and be respected as carers and actors in the community. Our data suggests this was both through indirect support and on-going mentoring and more directly through providing stipends. According to Campbell et al (2009) stipends in particular were critical in building the women carers' sense of confidence and ability to make a difference and we conclude similarly. Without such external support the women carers were once again returned to their structurally weak position in their community, where they were looked down upon by the leader of the Entabeni Project, the community and external organisations because of their position as women, carers and volunteers.

Paul Farmer (2005) has suggested that the idea that members of very deprived communities are capable of sustaining projects seeking to tackle complex social problems is unrealistic. Similarly Kumar and Corbridge (2007) suggest international development agencies are too grand in assuming that small, locally driven projects can effect widespread social change. Our findings exploring the long-term impact of a well-documented case study support this assessment. At a local level community responses to HIV/AIDS are unlikely to be sustained by

eager communities wanting to effect a change, rather they will be sustained when external organisations, in particular the public sector, but also NGOs, provide meaningful support that engages at the level of what is needed by such projects (Gibbs, Campbell et al. 2014). Even where sustainability and ownership of community mobilisation approaches is achieved, such as the Avahan Project, it is incredibly unlikely that this will happen in short timeframes and without external NGOs playing a significant role in achieving this objective. The sustainability of local community projects after short periods of time remains highly unlikely and without changing this approach risk further entrenching the disempowerment of those most marginalised.

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