Community entry points: Opportunities and strategies for engaging community supported HIV/AIDS prevention responses

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Disclaimer

This report does not purport to represent the views of the Global Fund to fight AIDS, TB and malaria.

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EXECUTIVE SUMMARY

Research focus

Against a backdrop of limited public service responses to HIV/AIDS, community level responses have developed over the last twenty years in the form of a wide range of community civil society service organisations (CSOs).

This research sets out to understand the prospects of this development for improving HIV prevention efforts at community level; and how they may be pursued.

Research methods

The study commenced with a literature review focussing on community and local level responses to HIV prevention and civil society engagement in HIV prevention.

Other sources of information used include: 1) data collected in CADRE's ongoing community-level engagements and HIV prevention communication training in east and Southern Africa; 2) secondary data from research previously conducted by CADRE; and 3) primary data collected in the Eastern Cape Province of South Africa.

Primary data were collected in a series of seven focus groups and two in-depth interviews that were conducted in Xhosa and guided by standard ethical protocols. Data were translated into English in the process of transcription, entered into nVivo8 — a qualitative data management package — then coded for themes and sub-themes and examined for relationships.

Data and perspectives from a wide range of contexts within South Africa and other countries in east and Sothern Africa has helped to strengthen the generalisability of the findings and recommendations.

Findings

Review of previous work

- Large scale funding programs and in-country sub-granting programs use CSOs to get services closer to the ground, but do not make any real commitments to, and show little appreciation in funding terms, of the value of strengthening these community HIV/AIDS response assets.
- The discretionary component of funding support to CSOs is limited, and funding discourses display little appreciation of the value of supporting organizations' medium or long-term plans.
- The new funding modalities emphasise government budget support and this has unwittingly restricted the flow of funding to civil society organizations because of inefficiencies, and in many cases mistrust, on the part of national AIDS authorities and government departments. The participation of the civil society sector in these bodies is limited and widely recognized as tokenistic.
- There is evidence of a decline in funds channelled through local NGOs with a corresponding increase in funds being channelled through international NGOs.
- Many organizations barely develop apart from their ability to render particular services; and very few CSOs show indications of moving to any kind of sustainability.

- Transaction costs of participation in national CSO engagement programs are high. More time is spent pursuing funding or managing funding and programs have over time acquired more sources of funding for equivalent size of funds.
- Civil society is being shaped by the funding environment. Independence and advocacy, traditional hallmarks of civil society, appear to be in short-supply.

South African fieldwork findings

1. Community organisations working for HIV prevention

The following themes are discussed: the birth and growth of community organisations; community HIV/AIDS workers; the roles of CSOs in HIV prevention; roles in HIV prevention; capacity building and training; and limited vision and understanding of prevention.

Community organisations working in HIV/AIDS represent a range of interests and motivations. The circumstances leading to their development requires personal drive as well as opportunity.

There is need for systematic training and education at the level of community caregivers and health workers that has not been systematically developed in the country, although there are pilot projects working towards such ends.

2. Volunteers in HIV prevention

The following themes are discussed: volunteer motivation; volunteer retention; volunteer training; and merging volunteerism, career development and economic opportunity.

High degrees of volunteerism are sustained by a delicate balance of community mindedness and opportunity.

Retention of volunteers is critical to the sustainability of many HIV/AIDS community organisations. But there is a limit to their motivation as they are mainly unemployed people and any efforts to support their own communities detract from their capacities to support their own families. Besides, the stipends received often do little more than cover expenses.

The possibility of steadily training volunteers and offering them opportunities for advancement and marketable skills is key to their retention and replenishment when they move on.

3. Modes of community engagement in HIV prevention

The following themes are discussed: local understanding as a starting point; community access and influence; bridging and linking social capital; HIV/AIDS awareness; home-based care; HIV counselling and testing; support for people living with HIV; income generation as an avenue for HIV prevention.

Community level HIV/AIDS workers have rich opportunities to pursue prevention goals through: excellent local knowledge; good community access and credibility; linkages within and beyond communities; and opportunities to promote HIV prevention in the course of home-based care, VCT and HIV support. However, these opportunities are not seized on to the extent that they could and should be. This is mostly because prevention practitioners at community level are not sufficiently knowledgeable about how to achieve

HIV prevention in targeted ways and to selectively use the range of prevention approaches available. The entry points are open but they are not used to good effect.

4. Cultural, religious and symbolic approaches to HIV prevention

The following themes are discussed: tradition and culture in HIV prevention; faith responses; and symbolic and psychological aids to HIV prevention.

It was found that cultural and religious practices and institutions provide some entry points to HIV prevention. However, their contribution to HIV prevention is limited, sometimes contested and difficult terrain on which to conduct HIV prevention.

The research revealed a range of symbolic 'assets' which are used to draw people into HIV prevention, reflecting deeply held values and aspirations at individual and community attitudes.

5. Funding and support for community-level responses

The following themes are discussed: availability of funds; sources of funding and support; government funding and support; funding tied to capacity building; competition for funding and clients; and the threat of large scale international programmes.

The funding situation for community level HIV prevention programmes is not conducive to effective planning and consistent service provision. In the absence of some form of national programme for supporting HIV prevention at community-level there appears to be little prospect for a more systematic, collaborative and effective approaches to prevention at community level. The skills and capacities of community organisations are also not likely to significantly improve in the current situation which appears to be beset by survival concerns rather than growth and improvement.

6. Strategic management

The following themes are discussed: monitoring and evaluation; local strategies and coordination.

Monitoring and evaluation practices and expectations on the part of funders and government need to develop beyond simple output reporting. For any community-level organisation contribution to community-level outcomes is needed if community-level effects are desired. This requires an entirely different M&E approach, and it requires community-level HIV prevention strategies.

Local coordination needs to be underwritten by local HIV-prevention strategies based on understanding of local HIV transmission dynamics and opportunities of local organisations to work together with shared goals and a joint plan.

Recommendations

Recommendations are made about ways of supporting community-level HIV prevention responses through more effective engagement of community-level civil society service provision and civil society more generally. Three spheres of activity and support are described.

1. Community-level HIV-prevention coalitions and strategies

- Form a local coalition for HIV prevention

- Identify existing community HIV prevention resources and entry points for HIV prevention
- Undertake a local level review of HIV transmission dynamics and prevention needs
- Develop and implement a joint community-level HIV prevention strategy
- Manage implementation of the strategy

2. Capacity building for community-level HIV prevention

- Establish national agency to support community-level HIV prevention responses
- Develop needed guidelines for community-level HIV prevention
- Support HIV prevention training

3. National strategy and funding to support community-level HIV-prevention

- Review of the HIV/AIDS CSO environment at country level
- Develop national strategies for civil society service provision at community level
- Develop national funding programme for community-level HIV/AIDS prevention

1. SCOPE OF RESEARCH

The Centre for AIDS Development Research and Evaluation (CADRE) was contracted by the Global Fund to fight AIDS, TB and malaria to conduct research into the local level systems effects of large scale funding in three South African Communities through two contracts in 2005-2006 and 2008. The results of these contracts have been used to inform Global Fund reporting.

The first round identified community-level needs for financing in the three study sites, identifying responses to ART, and changes in community-level responses to HIV including stigma and discrimination at the community level. The findings suggested more than ever that the 'reality of AIDS' is permeating throughout communities and people have moved beyond denying knowing people with HIV/AIDS or questioning the severity of the epidemic.

The follow up to this work involved documenting models of funding and coordinating community-level responses to HIV/AIDS through a review of eight community-based organisations. Three areas of support to strengthen community based organisations were identified: predictable financing, training and capacity building and coordination, alignment and advocacy.

The next round of work in 2008 identified specific organisational needs and appropriate actions to lead to more efficient community organisations. The actions to support these needs included strategic planning, management capacity development, staff retention, community networking, and financial planning and resource mobilisation. It also identified organisational efficiencies gained from bridging the gaps.

A third and current round of work seeks to expand on these previous pieces to look at lessons learned from strengthening the prevention response in community settings. The research focuses on the challenges of, and efficiencies gained through a community based model of service delivery. It looks at how communities develop indigenous prevention messages and methods and provides suggestions on how to increase effective service delivery of HIV prevention through promoting access to and absorption of funds by community organisations.

2. REVIEW OF LOCAL RESPONSES TO HIV/AIDS

The focus of the literature review was on East and Southern African contexts with a particular emphasis on the South African setting where the empirical component of the research was due to take place.

1. Taking stock

There has been little documentation of the scope and scale of local level responses to HIV/AIDS in sub-Saharan Africa.

Community-level responses to HIV/AIDS predated the large-scale funding which is now enabling support for community interventions as a programmatic response to HIV/AIDS. Many of the activities that have become institutionalised in national and global-level plans were in fact pioneered on the ground by community welfare organisations, churches and groups of infected and affected people (Rau, 2006). Some of the clearest successes in confronting the HIV epidemic have been linked to the active role played by local level actors. (Epstein, 2007; Low-Beer and Stoneburner, 2004; Panos, 2003;

Thornton, 2003)

The principal way of supporting community-level responses has been through funding civil society organisations that are in a position to conduct appropriate interventions at community level. By the mid-1990s civil society organisations were already named as 'partners' in multi-sectoral programmes and increasing attempts were made to support them as a critical element of HIV/AIDS responses.

The category 'civil society organisations' (CSOs) is broader than the rubric of 'community-level interventions'. 'CSO' encompasses: international non-governmental organisations (NGOs), national watchdog and advocacy organisations, forums and umbrella bodies; faith-based organisations (FBOs); national NGOs with multiple branches; community-based organisations (CBOs) specific to particular communities; tradition and custom-oriented associations; as well as a plethora of informal associations and interest groups at community level that may be long-lasting or transitory in duration.

The past two decades has seen a steady deepening of the involvement of civil society organisations in the provision of social services, emergency and humanitarian relief, and development programmes in many countries. Although non-governmental institutions and church-based health care systems have been providing services for more than a century in some sub-Saharan African countries, the role of non-state actors became much more pronounced and widespread during the 1980s, when Structural Adjustment Programmes severely curtailed levels of spending and constrained the capacities of states. Fuelled in part by an economic and governance climate that favoured outsourcing roles to non-state 'service providers,' NGOs moved into the gap and began to take over the provision of services in certain sectors, such as health, sanitation, education and rural development – in some cases surpassing the role of the state itself (Clayton et al., 2000). During the 1990s, NGOs emerged as one of the main vehicles for delivering official development aid to its intended beneficiaries (Fowler, 2000).

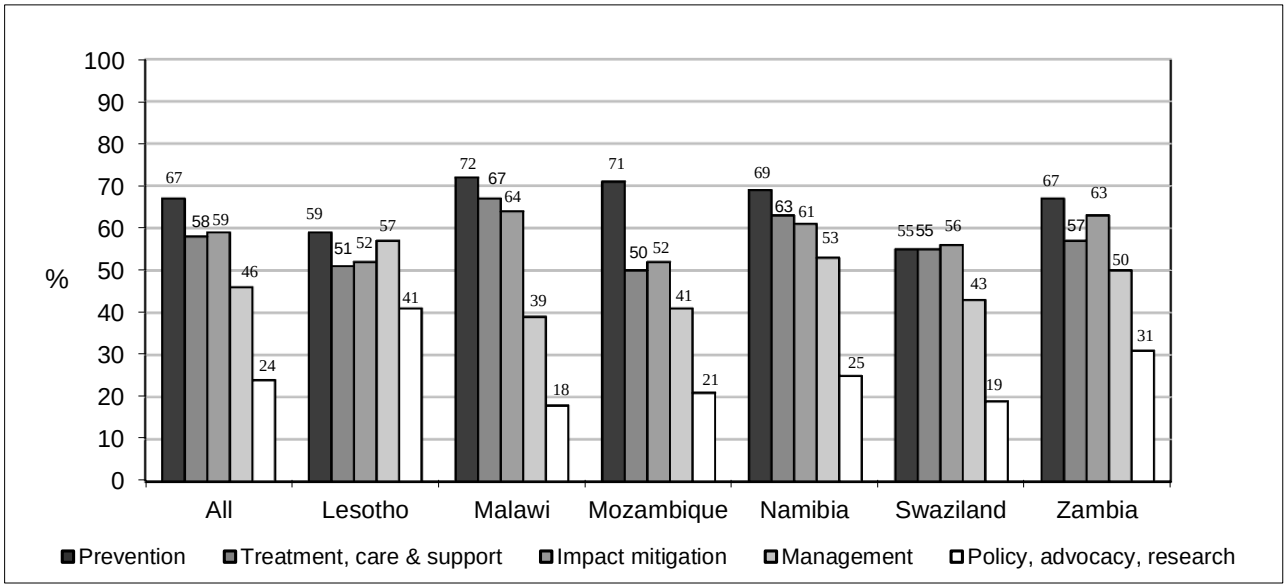
Worldwide growth in numbers of civil society organisations over the past two decades has been termed a global 'associational revolution' (Salamon, 1994). Although documentation of the size and capacity of civil society sector is limited, certainly in East and Southern Africa during the early 1990s, donor agencies 'discovered' civil society and enlisted CSOs both rhetorically and programmatically. Although development agencies in donor countries have long channelled some support to their own international development NGOs for work overseas, the 1990s saw a major shift from 'support for NGOs' to the less clearly defined 'support for civil society'. Civil society came to the forefront alongside a range of normative concepts including 'good governance,' 'partnership' and 'participation' (Wickramasinghe, 2005) that have since become embedded in development assistance strategies.

Research in seven East and Southern African countries (Birdsall and Kelly, 2007; Kelly and Birdsall, 2008) shows that growth in numbers of HIV/AIDS oriented civil society organisations commenced in the early 1990s, and reached a peak between 1996 and 2004, where some countries experienced growth well in excess of 1,000 CSOs. Growth was a response to the emerging realities of HIV/AIDS at the community level, and increasing financial support for civil society responses on the part of international donors.

In most countries in the region this involved the formation of hundreds of new CBOs, FBOs and NGOs, as well as the re-orientation of many existing organisations to HIV/AIDS. World Bank programs to support decentralized responses to HIV/AIDS and more recently, PEPFAR and Global Fund grants have helped to consolidate these

developments through an emphasis on using CSOs to initiate local responses. This has been paralleled by somewhat less successful attempts on the part of national HIV/AIDS authorities to work more closely with and in some cases fund the civil society sector through sub-granting programs. More is said about support for civil society responses below.

Figure 1: Percent of CSOs conducting different HIV/AIDS response activities in 2005



(Source: Birdsall & Kelly, 2007)

It is notable that civil society organisations are involved in most areas of response in each country with the highest proportion involved in prevention. This is illustrated in Figure 1 (above) which reflects findings of a 2005 survey of civil society organisations in six countries. However, CSOs are funded largely to provide specific prevention services managed by larger programmes and have relatively little involvement in determining the focus of such programmes.

As these developments occurred, the distinction was increasingly blurred between the organisations that were formed to facilitate activities and programs at community level, and the idea of community driven responses. This is not surprising since community-level organisations have been the principal point of contact in developing community-level interventions for HIV/AIDS. In fact, many civil society organisations have developed at the point of contact of external assistance programs and members of communities.

The focus of this research is on questions around opportunities for and challenges facing community-level HIV prevention responses. There is no question about the need for this, especially since national strategic plans for HIV/AIDS and global health initiatives espouse the importance of community-level responses. In its Round 8 call for proposals the Global Fund included the theme of community systems strengthening. This was an interesting development and opened the door for initiatives that recognise the community rather than the specifically organisational foundations of AIDS responses. However, there are questions about whether the strategies used to support civil society responses to HIV/AIDS are compatible with the broader motivation and the goal of supporting the development of grass-roots community responses.

There is much we do not know about the extent, shape and impact of community

responses to HIV/AIDS. There has been little systematic study of local level responses to HIV/AIDS, although the grey literature contains many case studies of locally oriented projects. Some of the clearest successes in confronting the HIV epidemic have been linked to the active role played by local level actors (Low-Beer and Stoneburner, 2004; Panos, 2003; Rau, 2006; Thornton, 2003).

Civil society action on HIV/AIDS long predated the idea of 'comprehensive programming' and the large-scale funding which is now enabling its implementation. Many of the activities that have become institutionalised in national and global-level plans were in fact pioneered on the ground by community welfare organisations, churches and groups of infected and affected people (Rau, 2006). The official embrace of civil society organisations as 'partners' in multi-sectoral response, public acknowledgement of their contributions, and commitment to make funding and resources available to them leant support to and accelerated CSOs' practical involvement in HIV/AIDS response activities.

CSOs have commonly been cited as the leading forces in the evolution of community-based models of care and support to affected people, including orphaned children (Foster, 2002; 2004; Iliffe, 2006; Rau, 2006). In the absence of strong social safety nets, associations of community members have proliferated across the continent to meet social and material needs; with varying levels of outside support. Formal policies and frameworks - for example, national plans for support to orphans and vulnerable children - were only promulgated years after the burden of support had effectively, and by default, been devolved to communities. (Iliffe, 2006; Rau, 2006)

Foster (2002; 2004) describes the spontaneous, informal and 'ordinary' actions that are undertaken within African communities to support orphans and vulnerable children. He notes that such community initiatives are usually started by small groups of motivated individuals who are driven by a sense of obligation to care for those in need, against a backdrop of limited or non-existent public services. According to Foster (2002), these initiatives, which are "non-sensational and almost invisible to outsider and insider alike" (Foster 2002, p.99), generally share the same fundamental principles: reciprocity and solidarity; consensus-based decision-making (particularly around understandings of vulnerability and identifying those who need care); self-reliance (resources mobilised locally); local leadership; volunteerism (altruism emanating from sense of community ownership); and innovation in problem-solving. Local-level FBO involvement in orphan care is burgeoning and initiatives already supporting significant numbers of children are expanding without large-scale funding and technical assistance, and with considerable resources in the form of volunteer support. Foster (2004) concluded that the cumulative impact of this local-level activity is significant and that, in the long run, local actors are better placed to respond to changing needs in orphan care than are large, external agencies.

Unfortunately there are no similar studies of the role of community organisations in HIV prevention and these are more difficult to achieve since the effectiveness of HIV prevention programmes cannot be measured as easily as can support to orphans. Claims in the area of prevention are more speculative.

Epstein (2007) suggests that it is not finance, or technical solutions, or programme management expertise that has made the critical difference in reducing HIV incidence and improving impact mitigation. The key to successful AIDS projects resides in "something for which the public health field currently has no name or program. It is best described as a sense of solidarity, compassion, and mutual aid that brings people together

to solve a common problem that individuals can't solve on their own." (Epstein, 2007, p.xii). Collective efficacy, or the capacity for people to come together and help others they are not necessarily related to, and which surpasses what individuals can do for themselves, may be the key concept here. A spirit of collective action and mutual aid would be difficult to measure or quantify, but may be the decisive feature of successful HIV/AIDS projects.

If this is true it would have profound implications for the way in which local HIV/AIDS responses are developed, conducted and supported, which will be addressed below.

2. Funding and support

In important ways, new funding modalities and mechanisms, both national and international, have limited the unique contribution that civil society organisations can make to national HIV/AIDS responses (Oomman et al., 2007). The drive to rapidly intensify the scale of HIV/AIDS responses has involved using community organisations as implementing agencies for externally formulated programs. To some extent this has meant a loss to of the diversity and responsiveness of community driven responses, as formalised CSOs have emerged, working to project plans agreed with funders. To this extent, the concept of 'civil society responses' has strayed from the idea of community-level and 'community driven' responses. The latter are more organic and embedded in informal activities arising from pre-existing care structures within communities. There has been little analysis of the characteristics of these respective systems of care, but it is self-evident that much like formal and informal economies, the structures, processes and activities that maintain them are very different, and require different forms of support for their sustenance and sustainability.

The emergence of literally thousands of new organisations in the sub-region has also raised the spectre of a self-interested stratum of organisations, that do not necessarily reflect the vision of indigenous and community driven responses to HIV/AIDS. They certainly are being used at a large scale to deliver critical HIV/AIDS services, including prevention programmes; although critical questions about how the tendency of communities to care for their members are best harnessed, and how this can be done without undermining the propensity to care, are largely unaddressed and unanswered. Having noted the paucity of work on the character of informal systems of HIV/AIDS responses, we now focus on what is known about the challenges of funding them.

Funding challenges

A number of problems are listed below, associated with funding of civil society and ultimately community-level responses to HIV/AIDS. These are derived largely from our previous research (Birdsall & Kelly, 2007; Kelly & Birdsall, 2008; Kelly, 2008).

1) Existing policy and strategy constraints

Donor alignment with national strategic plans and country coordinating mechanisms does not give sufficient recognition to the contested terrain of HIV/AIDS responses that are evident at country level.

In Ethiopia, for example, there is very little CSO involvement in HIV/AIDS responses generally. In countries like Mozambique and Tanzania, civil society was not historically engaged in any meaningful way and in many countries civil society was largely led by international organisations. There have also been attempts in some countries to re-engineer civil society such that it is more compliant with the thinking of national AIDS

structures. For example, in Tanzania the national AIDS council has reshaped the organisation of civil society by sponsoring new national representative bodies of people with HIV and civil society organisations that compete with and are contested by existing bodies.

Also country policies and limitations of social tolerance mean that the needs of important HIV/AIDS constituencies are often overlooked. For example, there are recognised concentrated HIV epidemics among intravenous drug users in at least five African countries, but there is only one country, Mauritius, with a programme aimed at the problem. In many countries in Africa same-sex relationships are illegal and there is strong evidence of greatly elevated HIV infection among communities of men who have sex with men, but again the problem is ignored because of the need to fund within the parameters of officially sanctioned programme parameters.

Current international discourses around HIV prevention in high prevalence countries have further exacerbated this by emphasising the need to focus on addressing the factors sustaining generalised epidemics, de-emphasising the needs of marginalised communities with concentrated epidemics; and also taking attention away from an interest in cultural responses to HIV/AIDS that were emphasised in the period between about 1995 and 2005.

2) Limited and project oriented capacity building

Large scale funding programmes and in-country sub-granting programmes use CSOs to get services closer to the ground, but often do not make any real commitments to, and show little appreciation in funding terms, for the value of strengthening these community AIDS response assets. Capacity building efforts are offered sporadically and often associated with particular service delivery needs under specific time-limited programmes, but real attempts to build the civil society sector as a whole and to strengthen government attempts to engage civil society are generally not well developed.

The future of most CBOs and NGOs is fragile because they mainly depend on seasonal funds from donors for their operations. Often very limited resources are made available for organisational running costs, salaries and equipment.

CSOs are increasingly engaged as service providers with activities closely prescribed. Civil society is being shaped by the funding environment. Independence and advocacy, traditional hallmarks of civil society, appear to be in short-supply; as are diversity, innovation and rootedness in communities. It is ironic that these are among the reasons why civil society was deemed in the first place to be seen as a valuable asset through which to invest in HIV/AIDS responses.

3) Ascendance of large national and international CSOs

The transaction costs involved in funding many small organisations weighs in favour of larger grants to fewer organisations. This has meant that funds have tended to flow to larger CSOs in a position to manage larger projects and disburse funds or offer technical assistance to smaller national and community CSOs that often do not have the capacity to manage or utilise funds. This has favoured larger national and international CSOs.

This trend is illustrated by data from Zambia. It was found that between 2005 and 2006 spending from external sources to local CSOs decreased from 69% to 17%, whereas external source funds being channelled through international NGOs working in-country increased from 38% to 56%. (MOH & NAC, 2008)

It must be noted that National AIDS Spending Assessments (NASA), where these have been done, do not track the geographic spending of funds for civil society and provide only minimal information on the focus of civil society funding. There is remarkably little information available about how much funding has flowed to community level, what it has been used for and what has been achieved at the level of outputs, outcomes and impacts.

4) Government budget support

The new funding modalities have emphasised government budget support and this has unwittingly restricted the flow of funding to civil society organisations, because of inefficiencies and in many cases mistrust on the part of national AIDS authorities and government departments. Participation of the civil society sector in these bodies is limited and widely recognised as tokenistic.

The net effect of the new funding modalities has been reduction of direct bilateral funding relationships, which were the mainstay of support for the growing number of medium-sized country CSOs. Many long-standing, innovative and efficient organisations are facing new funding crises because of the steady retreat of direct and bilateral assistance.

Civil society organisations have found it increasingly difficult to strike up relationships with funders and they find themselves competing for funds to provide services under national sub-granting programmes; ironically often managed by international for profit-companies and NGOs.

5) Funding not suited to organisational development needs

Many organisations barely develop apart from their ability to render particular services; and very few CSOs show indications of moving to any kind of sustainability.

More time is spent pursuing funding or managing funding and programmes have over time increased in number of sources of funding for equivalent size of total funds.

The discretionary component of funding support to CSOs is limited, and funding formats display little appreciation of the value of supporting organisations' medium or long-term plans.

6) Funding sensitive to civil society organisation needs:

On a more positive note, in some countries there are special mechanisms developed as niche funding opportunities for civil society organisations: for example, a fund to support medium-sized NGOs to scale up innovations (Rapid Funding Envelope, Tanzania), and a small grants funding initiative in Namibia aimed at assisting newly formed organisations.

In South Africa there are CSO support programmes in both departments of social development and health, to enlist the support of organisations in providing basic services in early childhood development, home-based care and community care.

In these cases and elsewhere there is scant evidence of well thought models in place. There is barely any articulation of whether CSO service basic service delivery is an interim measure or long-term strategy. There is also little political clarity about what this commitment represents for government and civil society in the long-term.

3. The South African context

South Africa has a strong history of an active civil society sector which in the past has

operated through community-based activism and human-rights advocacy. This is to some extent mirrored in the HIV/AIDS field by South Africa's advocacy-oriented 'Treatment Action Campaign'. But this is in many respects an exception to the norm. There has been considerable evolution of civil society structures and forms of organisation in the post-Apartheid era (Nauta, 2004). There has been a strong emergence of semi-professional non-governmental organisations involved in service delivery. There has also been diversification and specialization of community-based organisations and growth of faith-based organisations (FBOs) providing a wide range of social services

The only attempt to take stock of the size and scope of the non-profit sector (not HIV/AIDS specific) in South Africa (Swilling and Russell, 2002) is based on a 1998 national survey. The research identified 98,920 non-profit organisations with the majority (53%) being less formalised community-based organisations concentrated in poorer communities. The non-profit sector at the time employed 645,316 full time workers and in 1998 mobilised nearly 1.5 million volunteers.

There have been profound changes in the jurisdiction of social services in the country in the post-apartheid era with the dissolution of a number of key independent statutory service organisations such as the Child Welfare Society, and the increasing prominence of government structures for social development and services. Government social workers are largely consumed with the massive bureaucratic task of administering a growing cash-bashed social assistance programme, and there has been a resulting crisis in terms of meeting the care and support services that were the traditional business of the social service sector. Civil society organisations have struggled to make up the shortfall. It has been estimated that 80% of the social service sector in South Africa is delivered by civil society agencies (Loffell, 2007). They are partly funded by government, but such support is notoriously inconsistent and unpredictable and the security of basic social services, for example support to orphans and vulnerable children, is dependent on fund-raising efforts by service providers.

Civil society provides an unacknowledged and under-supported set of critical social services. Any efforts aimed at preventing HIV infection among vulnerable children and young people is largely left in the hands of the civil society sector. This is all the more the case in other countries in sub-Saharan Africa where, apart from Namibia, there are no state social work services at a national scale. The civil society sector provides the main social network framework in most countries in the sub-region.

Concerning HIV/AIDS in particular, there have been a few attempts to research the scope and scale of community-level responses in South Africa (Birdsall and Kelly, 2005; Campbell et al., 2005; Russell and Schneider, 2000; Teljeur, 2002).

The official national response to HIV/AIDS in South Africa has traditionally relied strongly on provincial public health systems for interventions such as condom distribution, voluntary counselling and HIV testing , prevention of mother-to-child transmission, and the roll-out of antiretroviral therapy. Inadequacies in government responses in these areas have led to massive involvement of civil society in filling the gaps and extending services. It is clear that over the last ten years at least, localised projects have emerged across the country to fill gaps in HIV/AIDS service provision in almost every area; but most commonly in prevention education, HIV support groups, home-based care, support for orphans and vulnerable children, and impact mitigation through activities such as food-gardening or savings schemes. But there are also CSOs providing more technical services such as anti-retroviral therapy and other biomedical services, and developing high-end mass media communications. The types of

organisations range from strongly regulated and highly professional to threadbare volunteer groups with little training and limited connections to HIV/AIDS organisational networks and funding.

The number of such initiatives can only be guessed at, but counting the members of a few networks, civil society sub-partners of the PEPFAR funding programme, and a number of multi-site programmes, a count of 1,000 organisations is quickly passed. The final tally may be a few multiples of this; especially if those organisations not primarily oriented to HIV/AIDS, but have a significant component of HIV/AIDS in their objectives, are counted.

In 2000, many of the CBO HIV/AIDS initiatives were in their infancy and quite 'precarious,' operating with limited resources, in single communities, with only occasional and limited external support and often not working with reference to guidelines or external parameters. This situation appears to have regularised due to the need to meet operating and reporting demands of funders.

Supported by international funding a growing group of national NGOs with multiple projects in different communities has emerged and they have effectively become sub-granting agencies to smaller community based organisations. They build the capacity of these organisations to implement standard programmes, often allowing variations in how a basic programme is implemented, but requiring reporting on a standardised set of outputs.

But there remain many organisations that are based in single communities. The scale of organisations in this category, many of which receive only occasional funding, is not known. Also many such community support activities fall under churches or community organisations that are not primarily HIV/AIDS oriented, and may not be recognised, even locally, for their contributions to HIV/AIDS responses.

It is also significant that there is little understanding of the scale or value of the contributions of volunteers, who are not always part of formal CSOs. There is likely a significant contribution to more formal programmes through volunteers educating community members about access to formal services, provision of psychological and spiritual support, and monitoring of health and basic health-care (Campbell et al., 2005; Kelly and Mzizi, 2005). This work is often done with few supplies, little support and no compensation. Such volunteer carers exist in many communities across South Africa and represent an already mobilised, but under-utilised resource for AIDS support.

Looking beyond South Africa and HIV/AIDS responses, it has been said that global institutions have 'consumed' local initiatives and formations; and local CSOs have increasingly struggled to define and sustain their own agendas in the face of financial dependency on external sources of funding (Fowler, 2001; Wickramasinghe, 2005). The result is a high-end of professional organisations and networks led by experts, who effectively become prime partners of major funders. Ultimately they become sub-granters to smaller organisations, including single-community organisations, with few inter-organisational linkages, little community contact and inadequate training for what they undertake.

However, there are encouraging signs that the HIV/AIDS civil society sector in South Africa is becoming progressively more organised. Recent consultative processes leading to development of a new National Strategic Plan have shown evidence of a more collaborative relationship between government and civil society, expressed mainly through the South African National AIDS Council, which has among its objectives to

create and strengthen partnerships for an expanded national response to HIV/AIDS in South Africa. It employs a full-time 'NGO sector coordinator' and expresses a desire to engage the civil society sector. But the efforts of some provincial health departments to engage civil society predate such developments by a number of years (Kelly and Marrengane, 2004). Gauteng and Western Cape provinces are notable for initiating programmes to coordinate and support community-level HIV/AIDS responses five or more years ago; engaging with communities directly through CBOs and also by fostering cooperation between provincial and municipal government structures.

The civil society sector has developed to the point of there being active civil society networks in the following sectors: disability sector, children affected by AIDS, law and human rights, men's and women's issues, faith based responses, traditional healers, traditional leaders, people with HIV/AIDS, and higher education, among others. The structure of the National AIDS Council, and the emerging provincial AIDS councils, allow for and encourage organised representation by sectors – although the complexity and layering of the civil society sector makes notions of representation difficult to envisage, except at local level. The most systematic support efforts towards this end have been conducted at local government level.

There are some strong examples of well led, comprehensive municipal responses to HIV/AIDS, especially in the country's cities (Kelly and Marrengane, 2004), but also in some local and district municipalities (Ambert et al., 2006) where local government has played a catalytic role in the development of coordinated community-led responses to the epidemic.

Notable exceptions aside, municipal responses to HIV/AIDS are often limited to activities such as organising occasional HIV/AIDS awareness events and putting up billboards with HIV prevention messages. Whilst these kinds of initiatives must have generated some value, there is certainly no strong evidence that municipal AIDS councils have been effective in coordinating effective HIV prevention responses.

By contrast the CADRE HIV prevention training in Zimbabwe showed evidence of a national programme for local level responses. This is supported by manuals, materials and training. It enlists the efforts of numerous CSOs and community-level structures; and is supported by district and community-level coordinating structures. Furthermore, the programme for local level HIV prevention is supported by a national fund with secure funding from a range of international donors. The programme was developed on the base of evidence and reviews of existing prevention efforts and needs.

4. Funding support in South Africa

There has been very little research on funding for civil society or local HIV/AIDS responses in South Africa. There is apparently no consolidated information about the amounts being spent by provincial departments on civil society support, and the donor funding matrix maintained by the national Department of Health (Ndlovu, 2005) keeps tally only of the amount of external funding provided to the Department.

Some detail from different sources helps to illustrate the context. The total amount of funding provided by donors to South African HIV/AIDS responses has grown significantly. The US President's Emergency Plan for AIDS Relief (PEPFAR) has allocated US$ 591 million to support comprehensive HIV/AIDS prevention, treatment and care programmes in South Africa for the 2009 financial year. In 2007, there were over 90 prime-partners and 300 sub-partners, and given the 49% increase in funding since

then, the number in 2009 is likely to be considerably higher. Some of these are government institutions, but most are non-state actors. Not all of the prime partners are South African and in 2005 a little more than half were South African entities and the remainder international, mainly American. Most of the larger non-state recipients are international NGOs which sub-grant within South Africa. Other large-scale funding programmes, including the Global Fund for AIDS, TB and Malaria (GFATM), have also provided large amounts to non-state actors in South Africa and the UK Department for International Development has funded the Department of Social Development in supporting community and home-based care.

It has been shown in other countries that international funding agreements and modalities of assistance can have a profound impact on the growth and development of civil society agencies working in the HIV/AIDS field (Birdsall and Kelly, 2007; Kelly and Birdsall, 2008). South African civil society is being shaped in ways that have not been documented or discussed; and there is reason to question the sustainability of a large cohort of funded organisations, many of which are largely service providers rather than organisations based in and staffed by community members.

There has been little understanding of how civil society organisations would best develop; for example, whether they should strive for specialisation in particular areas or whether they should grow progressively more comprehensive. A study of civil society organisations in South Africa (Birdsall and Kelly, 2005) showed that many are beset by multiple challenges and often grow into increasing chaos and unmanageability. They struggle to meet the reporting requirements of multiple funders and it is often funding opportunities rather than local needs and organisational capacity that determine what they undertake. It is as well that there have emerged a good number of organisational development service providers to support the many new and growing organisations (Goudge et al., 2003).

Provincial departments of health and the national Department of Social Development support civil society organisations working at community level. Departments of health support home-based care, and social welfare departments support community organisations in a more primary sense that includes capacity building as well as limited funding support. The latter programme constitutes a new and significant interest on the part of a national government department in enlisting civil society actors to fulfil primary government functions. It bodes well if it can be systematically developed, although political questions flow uneasily beneath the current of goodwill; because this in some respects means the government handing over one of its primary service delivery mandates to extra-governmental implementers.

Given the scale of civil society involvement in HIV/AIDS responses, the funding and development of the civil society sector working at community level should be the subject of much more attention.

This brings us back to the importance of recognising and supporting existing community based initiatives and the necessity of partnership building at the local level - to enhance coordination between various actors, to strengthen referral networks and information sharing, and to integrate various HIV/AIDS-related services.

3. METHODOLOGY

The methodology of the study is described in Annexure 1 and schematically summarised below.

Literature review

Community and local level responses to HIV	Civil society engagement in prevention

Data sources and data collection

Primary data (standard ethical protocols apply)

1. **NGO & CBO perspectives**

   Three focus groups: one each in a city, a small town and a rural town in the Eastern Cape Province of South Africa. A total of 30 participants, all engaged in HIV prevention.

2. **Rural community perspectives**

   Four focus groups – one each with a men's group, a team of male and female volunteer community HIV workers, home based carers from different villages, and an HIV-positive support group – all in a deep rural area in the Eastern Cape Province of South Africa. There were a total of 34 participants.

   Two in-depth interviews with an HBC leader and a prevention project team leader.

3. **HIV prevention practitioners**

   65 individuals selected to participate in the trainings as representatives of CSOs involved in HIV/AIDS prevention. They represented 48 CSOs (made up of CBOs, NGOs, national HIV network organisations), 3 international NGOs, and 5 representatives of government departments. Training was conducted in South Africa, Tanzania and Zimbabwe.

4. **Ongoing research**

   Data from an evaluation of a faith-based care and support initiative, conducted in urban informal settlements in the most underdeveloped region in South Africa and the largest metropolitan area of the country.

   Data from an ongoing study of communication and social mobilisation for supporting prevention of mother-to-child transmission of HIV in five sub-districts across South Africa.

Secondary data

1. Data from a six-country (Lesotho, Malawi, Mozambique, Namibia, Swaziland, Zambia) study conducted by CADRE on the changing dynamics of civil society funding and responses to HIV/AIDS (Birdsall & Kelly, 2007). This involved: a survey of 439 CSOs organisations; more than 50 interviews with donors, government HIV/AIDS agencies and civil society leaders; and case studies of local responses to HIV/AIDS and the support they receive.
2. Data from a study of the funding environment for civil society responses to HIV/AIDS in Tanzania (Kelly & Birdsall, 2008) and a case study of a Tanzanian community organisation's struggle to respond to HIV/AIDS (Kelly, 2008).

Data processing and analysis

Secondary data sources: These were mostly used to interrogate and qualify findings in writing the report and as sources in the review of literature

Primary data sources: Where interviews and focus groups were conducted in Xhosa, data were translated to English in the process of transcription. They were then entered into nVivo8 — a qualitative data management package — coded for themes and sub-themes and examined for relationships.

Primary and secondary data were then brought into dialogue with information from the literature review.

4. RESEARCH QUESTIONS

Having reviewed sources of information on community responses to HIV/AIDS, their evolution and current status, we set out to explore HIV prevention at community level in a South African context.

The community-level research conducted was oriented on understanding 'community entry points' to HIV prevention. The idea of community entry points refers to opportunities for HIV prevention that have taken hold in communities, and that can be supported and developed to good effect. 'Community responses' is considered to include community based structures and organisations, faith based organisations, local government, traditional authorities, and informal responses at community level.

Under the rubric of community entry points, four groups of research questions were developed.

1) Status of community mobilisation around HIV prevention

- How have community structures, organisations, groups and members responded or support HIV prevention?
- Is there a typology of community entry points and what can we learned from appreciating these different types?
- What are the indigenous prevention responses to HIV from within communities, as opposed to those generated externally?
- What prevention information is conveyed in community settings, and how is it conveyed?

2) Strengthening community-level prevention responses

- How are indigenous responses to HIV prevention precipitated?
- What HIV prevention services are delivered (external origin) in community settings and how have these been received?
- How are community responses planned and managed?
- How can community entry points be accessed and supported?

3) Strengthening collaboration and support

- What opportunities and challenges exist for effective collaboration between and with community-level responses?
- What are the relevant networks supporting HIV prevention at community level and how are these constructed?
- What government support is offered and how can this be improved?

4) Funding to build sustainability

- How do international funding and funding processes impact on community organisations?
- How do government funding and funding processes impact on community organisations?
- What evidence is there of indigenous self-funding, self-sustainability efforts?
- What are the funding needs at community level and how can they be addressed?

5. FINDINGS AND DISCUSSION

Findings are presented under eight headings: 1) community organisations working for HIV prevention; 2) volunteers in HIV prevention; 3) modes of engagement in HIV prevention; 4) cultural, religious and symbolic approaches to HIV prevention; 5) funding and support for community-level responses; 6) strategic management of community-level responses.

1. Community organisations working for HIV prevention

The birth and growth of community organisations

Some respondents spoke about their own paths to involvement in HIV prevention work at community level. There was a range of motivations, with respondents often led by circumstances as much as specific choices; finding themselves drawn in.

One such participant initially heard about HIV and AIDS on the radio. Subsequently she met a social worker who she asked "*Ey, I always hear about HIV and AIDS: what is it*?" The social worker invited her to a ChildLine workshop (ChildLine is a national telephone help-line service that also runs local support programmes in hotspot areas). She narrated the series of events that followed this initial chance encounter:

> *"I got all the answers at that workshop. And then I said 'Oh-oh: I'm next to the squatter camp here.' So I think this: no matter I don't know how, but there is something I must do within that community. So that's when I started to deal with the community. So then I go to the clinic, I introduce myself, and then the clinic said 'Uh-uh, not as an individual: you have to form an NGO' – I said 'Ok, fine'. So, there were volunteers already, doing the voluntary thing on World AIDS day, during the awareness days. So I collect them together and then we formed the NGO there. We call the social worker that is working at ChildLine, we get the information from her and then she called other people that were NGO's already, for us, to assist us: how to form an NGO, how to do a constitution and all that stuff and we register as an NGO. So that area – that squatter camp – gives me the push: I was eager to help, and assist, because it was so sad – it was painful."*

There are of course many different paths to the formation of CSOs, involving a mix of personal motivation, opportunity and support.

Consistent with the findings of the literature review there was evidence that CSO activities are present even in quite remote rural areas, and at much higher density in urban areas. These range in size and level of formalisation as well as in degree of specialisation.

The most notable distinction between these organisations is whether they are projects of larger programmes or independent. The form of CSO – informal group of people or club, CBO registered as a non-profit organisation, FBO as part of a church community support programme, or branch of an NGO – cannot be reliably predicted from the type of location. However, NGOs with multiple sites tend to be run from centralised, urban locations.

Even some of the poorest rural areas of the Eastern Cape Province in South Africa have some presence of HIV/AIDS-focused community organisations. These were characterised by one CBO manager as "*Small, small NGOs; they are in the very midst of people – they are staying with the people."* Many of these are new formations in the constellation of community structures and interest groups, creating a *"visible and vocal"*

presence, ensuring that HIV/AIDS needs are included in the set of concerns of community organisations.

At community level CSOs tend to be led and served by people with intimate knowledge of their communities, but who have some level of independence from community structures. This status of community organisations as independent community entities is important. HIV/AIDS work has to tackle taboos and stigma that surrounds HIV/AIDS in many communities. The independence of separately constituted organisations within communities, but led by community members creates a measure of distance which allows for advocacy and change.

Community HIV/AIDS workers

It is evident that in all but the very most remote settlements there is some reach of community HIV/AIDS workers, who are in most cases supported by CSOs. The number and reach of these volunteers has not been quantified in South Africa; and it would be of value for planning to have some understanding of this. They represent a significant opportunity for HIV prevention.

The idea of community HIV/AIDS workers being HIV 'ambassadors', 'champions' or 'advocates' is widespread in community organisations; and they often use such terms to refer to their staff and volunteers. It is also apparent that community members recognise these roles.

When community HIV/AIDS workers are well trained and have specific areas of knowledge they are seen by community members as the local 'AIDS experts'. Community members look at them critically and appraise the extent to which they lead by example. They also represent at community level the voice and interests of people affected by HIV and are often act as advocates for HIV prevention in relation to cultural, religious and community affairs.

A CBO leader explained the reach of her organisation in response to the question 'Who drives or leads community responses in your area?'

> *"We've got different groups, for example peer educators in different areas, and every group has a leader. At our offices we call all the leaders together, and give them workshops, or give them information – it's whereby they go to their villages and give that information to the community."*

The spread of HIV/AIDS volunteers and CBO employees through communities allows community members to get information when needed, often on an informal basis. HIV/AIDS information sharing may place in community meetings which do not have an HIV focus, allowing community members to "*gain something, because they have people who are sick maybe at home and they didn't know where to go…they can actually get information." (rural CBO employee)*

The presence of cohorts of community members identified by themselves as well as others as sources of information on HIV/AIDS is an opportunity to be built on.

However, at the same time some participants from CBOs in deep rural areas said that whereas their organisations as very well positioned to work with people at community level they are not guaranteed a favourable reception, "*Because [CBO activists] are well known by the community, in a way the community doesn't believe in them; doesn't see them as bringing something that will change their lives*." Their social standing and credibility is shaped and accorded prior to their being involved in HIV prevention.

Community members may tend not to take them seriously because of this – unless they have a special training or qualification that sets them apart as an educator in the community. For this reason CBO managers thought that whereas community-level activism is important it requires the support and visible endorsement of external authorities, such as government and professionals.

The roles of CSOs in HIV prevention

The voices of people living with HIV/AIDS and support for them at community level is almost entirely a product of civil society initiatives.

CSO's outputs are largely unmeasured. In concept they are seen as acting as conduits between community HIV/AIDS response needs and the needs of people affected by HIV/AIDS; often providing information, limited commodities and service provision know-how.

This does not imply an even coverage or consistent, efficient service delivery, nor does it imply that there is effectiveness of response. It seems that community-level services are largely a patchwork effort in terms of coverage, and service delivery can range from highly responsive to disorganised and lacking in sufficient skills.

It was claimed by one CBO leader that

> *"In the rural areas the NGO's [not distinguishing CBOs and NGOS] are playing a vital role, more than the government departments themselves… We serve [government] with the information, and then some of them bring the information back to us for the results, and say "You are doing well for this." They even try and say "Ok, you are an NGO and you are busy with the people's lives. But is there a way that you can help with this or this?"*

Such organisations work mainly through family visits and in community meetings. There is little doubt that in rural areas these organisations are the leaders in HIV response, and without them there would be no HIV prevention education and advocacy. These small CSOs serve a 'bridging capital' function. They span the divide between government and people, which is of special value in deep rural areas where government officials and service staff are most notable for their absence. For the most part people from such areas are expected to travel to small towns to receive government services, and even then, in small rural towns government services are often not found – apart from primary health clinics.

The lack of involvement of government services in HIV prevention is evident even in larger towns. As one participant from a city said about HIV prevention: "*It's dead from the Department [of Health's] side, but in the NGO's [CBOs] it's alive.*"

But this is questionable, and we found little evidence of strong and effective community HIV prevention programmes. As will be seen below, this is not because of the lack of good opportunities or effort, but because of lack of coordinated, strategic and systematically implemented prevention thinking.

In urban settings the functioning of community service organisations is generally rather different, with much higher density, meaning greater specialisation. Urban organisations are more focused on delivering particular services under programmes where outputs are prescribed. As one CSO leader from a small town described it, *"[They] focus more narrowly on their organisations' interventions, clients, needs and concerns, more rarely thinking of themselves as serving the community as a whole."* In other words they are

more oriented on defined and limited modes of service provision. These include specific and pre-packaged models of prevention responses such as the well known ABC approach, but also specific services assumed – often undeservedly – to lead directly to prevention outcomes such as HIV voluntary counselling and testing and HIV education dramas. These may contribute to prevention outcomes, but only when supported by other interventions without which their assumed impact will not be attained.

Roles in HIV prevention

Unfortunately HIV prevention as conducted by many CBOs is not a well focused programme area. Much activity is focused on community awareness raising events, and campaigns conducted around health calendar days (e.g. World AIDS Day, STI week).

In planning such events the energy is often directed at the setting rather than the primary activity of prevention. Involvement of dignitaries and musicians, planning of street parades and sports events, and production of t-shirts and posters appear to consume the time and resources available. At the end of the day when marquees are packed away the field is left bare. The activities are thought of as having been successful by virtue of the attendance or enjoyment of the event. There is often little understanding of how the event is supposed to work. Processes of education or change are not thought about or reflected on but simply assumed to have occurred. The outcomes of such events are based on simple awareness building, and miss the importance of targeting specific groups that need specific methods of prevention.

Data show that community prevention leaders in many instances showed little understanding of approaches to health and behaviour change communication models or approaches.

Whereas HIV prevention education is an activity included by CBOs in their range of activities, it is usually only listed as a primary activity of organisations focused on particular constituencies, such as pregnant women or young people. For others – although they conduct activities which could be used as opportunities for HIV prevention, such as HIV counselling and testing and home-based care – prevention is not at the forefront and is undertaken in a largely add-on fashion.

Unfortunately there is a tendency among such NGO/CBO managers to think of prevention as a separate intervention that will add to already overburdened workloads and human resources. There is a clear need to promote existing service provision activities as opportunities of HIV prevention. However, there is little evidence that this is done in an informed way.

As one such CBO leader responding to the possibility of a new concerted prevention drive in her community, said:

> *"We can't just have this good idea and say 'Ok, it's going to work': it actually means creating more jobs in our organisations, finding the right people – which is very difficult – and finding the funding for those people. So it's a very, very complex thing. It's nice to have this wish list, but in order to implement it on the ground, I don't think any of our organisations is positioned now – or will be positioned even a year from now – to do it."*

There is a stark tension between the awareness and responsiveness of community organisations to community needs and the service provision mandates of CBOs. On the other hand, as much as there is a need to respond to the daily crises and needs that arise,

capacity to do this is limited by the demands of funding contracts which involve key service delivery mandates, limiting flexibility and responsiveness.

One CBO leader of an organisation focused on care services wished that her organisation could have "*a multiple response - one that focuses on prevention as well*." This opportunity is afforded smaller and less formal community organisations where there is not such a strong designation of the core business of the organisation; and where 'everyone does everything'. But unfortunately they often do not have the particular prevention skills to go beyond awareness-raising; so the value of allowing a broader scope of functions does not strongly come to fruition.

Capacity building and training

There are organisations that provide training to CSOs for up to a few days in duration. But exposure to training is usually opportunistic and supply rather than need driven. Also training programmes are usually once-off with no follow-up or opportunity for supervised learning. Furthermore, there has been little done on the part of funders to ensure that basic competencies are present in organisations that they support.

Training has high social value. It elevates volunteers to new stature in their communities and gives them authority to work as educators. There was strong interest on the part of respondents to the idea of certificated training, as it allows recognition of their skills, is of value on CVs and makes them more eligible for paid work in the field.

'Accredited' training from a tertiary or reputable CSO institution is seen as particularly desirable. Given that many volunteers involved in HIV/AIDS work in the rural areas have low educational backgrounds, such educational accomplishments are particularly important and strong incentives to rural based volunteers.

Some organisations have manuals and guidelines to guide the work of volunteers and staff and most CSO leaders in the study had received some form of basic training for their work – in the form of workshops and internal training. The range of training areas offered in the civil society sector in most of the countries covered by our sources of data includes almost every area of CSO service provision – for example, PMTCT, treatment literacy, HBC, early childhood development support, HIV awareness, and HIV counselling.

However, there was little evidence of systematic training of CSO volunteers or staff having been educated as prevention practitioners. For the most part HIV educators are not adequately trained in understanding basic issues in HIV prevention such as: the selection of prevention methods according to specific transmission dynamics and sub-populations; the value of people being assisted to decide what approaches prevention approaches are most efficient and effective for them, and how to implement them; and addressing prevention needs simultaneously at different levels (for example, community norms, support services and individual behaviour).

There was little evidence in our South African data of systematic training on how to bring about behaviour change. Proven methods of HIV prevention do exist. For example, the 'Stepping Stones' HIV prevention training programme has been proved in South African contexts to be an effective HIV prevention tool for young people. Yet none of the organisations interviewed draw on this or any other systematised HIV prevention approaches. The overall finding here is that the significant numbers of highly motivated community organisation leaders and volunteers are not focusing on strategic or evidence informed prevention activities.

There are a number of national tertiary institution training programmes in South Africa, the most notable focused on 'HIV/AIDS management' and 'care and counselling'. However, in terms of education requirements the bulk of community HIV prevention workers would not be eligible to enter these programmes.

Limited vision and understanding of prevention

The prevention thinking of community-level prevention practitioners is limited and orients on particular kinds of activities, which are falsely assumed to wholly represent HIV prevention outcomes. In our South African data evidence on HIV prevention activities showed that they focussed mainly on services such as VCT, community awareness building about the presence of HIV/AIDS and the need for behaviour change.

It is widely believed in community organisations that VCT is the grail of HIV prevention. Yet there is no evidence to suggest that simply knowing one's HIV status has positive prevention outcomes. Without a range of supports and parallel programme outcomes its prevention possibilities cannot come to fruition. The same can be said about community awareness building. These two areas of prevention are discussed among others below, as entry points to HIV prevention rather than prevention methods on their own.

Our general finding is that there is very little evidence of systematically developed prevention strategies based on understanding of behaviour and system change processes that are facilitated towards specific ends. There was no evidence in any of the communities included in this study of comprehensive prevention efforts which work at individual, social network and community level. There are examples of this elsewhere in the country, but these are mostly situated in communities where there have been exceptional opportunities through being HIV intervention study sites or project sites for large extra-community organisations. There are many rural areas of the Eastern Cape Province, for example, where even basic awareness of HIV has not been promoted at community level. Rural participants in the study say that there are many villages in the Eastern Cape Province where there has been little to no HIV education conducted.

This group of young male community educators would be better advised to focus on their own peer group or possibly slightly older men. There were many other incorrect assumptions expressed about behaviour change and where the bulk of new infections are occurring, leading to poorly targeted prevention efforts.

Basic information about HIV provided at community level appears to be short on important information about the role of circumcision in HIV prevention, mother to child transmission of HIV and its prevention, STI identification and treatment, post-exposure prophylaxis and its availability for rape survivors, and HIV sero-discordance and prevention in couples.

It was notable that only one participant out of 28 participants in CADRE's HIV prevention training programme in the Eastern Cape had accessed the report on HIV sero-prevalence and behaviour at household level in South Africa. All recognised that the information in this report was important for their work. But they do not have the capacity to filter out information that could be of use to them. Understanding and interpreting such readily available information is a key skill lacking among CSO leaders.

It appears given the reach of community educators that an opportunity is being because of inadequate understanding of HIV transmission dynamics and prevention.

Conclusions

Community organisations working in HIV/AIDS represent a range of interests and motivations. The circumstances leading to their development requires personal drive as well as opportunity.

There is need for systematic training and education at the level of community caregivers and health workers that has not been systematically developed in the country, although there are pilot projects working towards such ends.

2. Volunteers in HIV prevention

Many respondents felt that more people need to be employed in promoting HIV prevention at community level, and that current efforts are far from achieving the scale of coverage needed. To this extent, inadequate funding was seen as the problem.

The prevailing reality is that community-level prevention responses rely heavily on volunteers and organisations supported by inconsistent government funding and limited other external funds.

'Volunteerism' requires individuals and groups interested in committing time and effort to serving a social need. It implies that people have the opportunity to make such commitments and there is much evidence of an ample supply of people willing to commit their time and sometimes their resources to community HIV/AIDS responses. However, their involvement is often not simply motivated by philanthropy, especially in poorer communities.

Given that many of the local responses encountered in this study are dependent on volunteer involvement it is important to understand the conditions that make this possible.

Volunteer motivation

Many CSOs are supported by management committees or boards who are often qualified and professional people who provide support and advice to organisations at management or technical levels. This stratum of volunteers is usually comprised of people who are employed, who do not expect compensation or support, and who gain satisfaction from the experience of contributing to their community. However, they are quite different from the volunteers who are at the delivery end of the services and who were described thus:

> *In this town, unemployment is so high... there are lots of people that we can mobilise, and we work with volunteers. The problem is that when you have unemployed people working with you - you've got to think about finances and sustainability." (NGO leader in a small town)*
> *"Most of the volunteers know they're there just to provide the services without the incentive, but in their hearts they expect something in return – how do we deal with that problem?" (CBO leader in a small town)*

Whereas it is easy to gain the initial interest of volunteers, in contexts of high unemployment, the same circumstances which lead to their availability limit their contribution and value. A CBO leader said, "*We need to involve people who have an interest in actually being involved and not bring in people for the sake of just having these people –they're there but they're not effective at all.*"

Some of the limits in value and effectiveness noted by participants were: lack of a

sufficient base of skills to make some volunteers trainable for the functions they are needed for; high attrition of volunteers and limited commitment when they are primarily motivated by opportunities offered; and failure to build a sense of having a meaningful and appreciated role in the organisation.

Volunteer retention

The culture of expecting compensation for volunteer efforts has grown over time. One respondent explained how she had been part of a community organisation when it started:

> *"We volunteered there without funding: way back then, it worked, but nowadays if you talk about volunteering, people withdraw, because they don't want to work without something: at least as the years go by. Now even in the rural area, if you talk about volunteering to the people- They say 'but what will we get?' Even at my home, when I wake up every day to go to work, they say 'oh, you waste your time, because at the end of the month, you have got nothing'."*

Although many of the respondents were themselves long-standing volunteers, they reported high levels of volunteer attrition.

Volunteers trained to undertake particular tasks within funded projects over longer periods of time can only usually be retained with stipends, support and training and by the feeling that they are making a meaningful difference to the lives of those in their communities. They are given responsibilities under titles such as 'home-based carer', 'child care advocate' or 'support group facilitator' and their stipends are budgeted for in project funds. To this extent they stand between being employees and unpaid volunteers.

A participant pointed out that volunteering puts strain on the family, especially when it is unpaid.

> *"When you do the voluntary thing, you have to get the support from your family first, because it demands a lot. So if your family support is there – your carers' support is there – you'll support the carers too, in their problems."*

Not only do volunteers need support, but they derive support from each other. A participant leading a CBO and who was previously a volunteer said:

> *It gives all of the group strength, because we all have now one vision, to change the lives in our community. So, it was one, and now it's fifteen: and then, how do you push that vision to more than 15? How do you? That's the question. So, you will try, and try – but when the funding comes in it makes it easier."*

Community organisations often get high levels of dedication and commitment from volunteers, but the core of volunteers always needs to be developed with care. This takes time for ensuring that volunteers both feel enriched and valued for what they do and feel that they are not being used or exploited. Volunteers may feel exploited when other volunteers get higher stipends or benefits, when they feel they are doing the work of paid workers, or when they feel that the cost to them of volunteering is greater than the gain in terms of compensation, support, training or personal satisfaction.

There are many complexities around this. On the one hand labour unions are increasingly arguing that payment of stipends should meet minimum wage requirements and standard employment practices, and on the other side CBOs with little funding are not able to cover more than costs for their volunteers, and would have to cut down on the number of volunteers limiting their reach and coverage.

The entire situation is made more complex by uneven payment of monthly stipends for similar kinds of work; and in some cases inconsistent payment by organisations when funds are not available. The government departments that have programmes for supporting volunteers are widely criticised for inconsistency and lack of transparency or systems around the provision of stipends. The flow of funds is inconsistent and doesn't allow for planning or measured development. The entire area was described as a "mess" from the point of view of organisations most in need of this support.

In other countries, Tanzania being a case in point, fees are sometimes paid to community members for attending meetings and trainings which are for their own benefit and a perverse system has developed where people are being paid money to serve their own communities at rates which exceed well-remunerated work. This has raised suspicions around such activities, which tend to be characterised as profiteering.

Another issue of concern is that community members are sometimes suspicious of those who undertake volunteer work, saying that they are motivated by financial opportunities.

These issues certainly muddy the appealing idea of community members volunteering to be of assistance to their own communities and feeling that they have a duty to assist members of their communities in need.

The entire area of volunteer retention and the status of volunteers as community members serving a community duty or calling versus being workers and employees is in much need of a review and consultative policy formulation processes.

Volunteer training

There was agreement among CBO leaders that most volunteers are at least partially driven by an urge to help their own communities. But in addition, many young people are drawn to do volunteer work because it provides them training, work experience and an opportunity to begin building a CV and career. This is made all the more attractive when this involves 'accredited training' or opportunities to be exposed to new things.

This is important and must be built on. It requires a review and development of the training needs for HIV/AIDS responses and creation of a stratum of community-level practitioners who may go on in due course to develop careers in their areas of skill. This is already happening in South Africa in at least three notable areas with accredited and certificated trainings for auxiliary child care workers and early childhood development practitioners and home-based carers.

Similarly it was pointed out by a Child Welfare Society participant that Child Welfare South Africa trains and supervises volunteers - some of whom are foster parents. Volunteers are trained using a specific curriculum and their work is guided by a manual that they follow in house-to-house visits. When they identify problems, they have the opportunity to refer these to Child Welfare's social workers, who then intervene. Whereas there are difficulties involved in finding time and expertise to supervise them all, and *ongoing* training, the idea is a strong and promising one.

It was strongly felt that formalised and accredited [understood as a certificate which could demonstrate that they have specific skills] training courses help to build the sense that participants are building careers for themselves that may offer future formal employment opportunities, or which may be recognised should they move to another area.

Participants in a different focus group note that they had given of their time for up to 9

years without any real help from government and nothing to show by way of accomplishment. Members of an HIV support group members in a rural area pointed out that to be given some kind of accomplishment, such as in a certificate form, also makes them feel valued for their time and efforts.

Respondents spoke of the need to mobilise volunteers who are already trained but not active:

> *"We see them in the township, some of them are doing nothing because they are not attached to organisations anymore and they don't have that drive anymore. There are also ex- Treatment Action Campaign activists: where are they? Also, the municipality could have some data on people who were once involved in the health clinics, who were volunteers and are no longer involved. At least they've got the basics, and we know that they are trainable." (CBO leader small town)*

This was echoed by participants in another focus group, who added trained nurses, social workers, counsellors and traditional healers to the list of underutilised community human resources. As one participant says, "*We've got assets in the communities – we've got churches, we've got traditional healers, we've got counsellors, we've got retired nurses, social workers, and even families – who we don't try to bring in and make use of*."

There is a range of less systematically trained practitioners evident in communities, including child care supporters and various forms of peer educators. Very often training in these areas is not sufficiently in-depth or incremental to amount to development of semi-professional skills. Even in some areas where there is a need for this it has not developed. For example, those trained by a local VCT centre in the study are clearly not adequately equipped as VCT counsellors. Their participation at an HIV prevention training showed that their understanding of HIV prevention needs and opportunities is inadequate and certainly not informed about emerging ideas in HIV training, or the use of counselling as a prevention approach.

All of the above points to a need to systematise the volunteer sector if it is to realise its promise in HIV prevention. This will require that funders, governments and CSOs come together to develop this large resource on the basis of a set of shared principles.

In short there is a need for drawing on and systematically engaging the opportunity offered by the many people who are willing to serve their communities providing it does not come at a cost to them that they cannot afford. Volunteering can come at a cost to self and family and the balance between service and self-gain can and must be more adequately managed if this opportunity is to be optimised.

Merging volunteerism, career development and economic opportunity

One participant noted the need for training courses to be 'accredited', so that volunteers are not only being prepared to provide services, but also equipping them with skills that are transferable and marketable.

It was also suggested that training for prevention should be combined with income generating possibilities. Civil society organisations were not particularly forthcoming in making promising suggestions, other than emphasising the need for some security in terms of expectations of receiving stipends.

Both in the current data and in other studies we have conducted on community-level HIV/AIDS responses – notably Birdsall and Kelly (2007) – we have noted examples of community organisations that have engaged rather than averted their gaze from the reality

that volunteers also hope for economic sense. They have created viable and lasting loan schemes for beneficiaries (Kelly, 2008), used their CBO premises and facilities in starting and running small enterprises. They have also encouraged economic activity among people at particular risk of HIV exposure, often women and young people. There has not been much systematic study of this area of HIV/AIDS responses apart from research on small grants and loan schemes.

The idea that money and financial opportunity are corrupting influences in the civil society sector is often evident in discussions about the role of CSOs in HIV/AIDS responses. Yet, the economic realities of most African communities mean that those who start or volunteer in such organisations see the opportunity as both in the interest of the community and an opportunity to address their own needy circumstances.

If this is accepted as inevitable and worked with, there are opportunities to increase the long-term viability and sustainability of community services. As has been pointed out in the literature review, in most countries in sub-Saharan Africa including South Africa, civil society organisations provide the bulk of social services (excluding social grant administration in South Africa). Better understanding and addressing of attitudes and motivations of leaders and workers within these organisations is important. There are opportunities for improving the effectiveness of such services through more dependable, consistent and better trained community volunteers, and this requires rethinking the conception of volunteerism, leaving behind the model of an economically empowered person doing good deeds for others.

Conclusions

High degrees of volunteerism are sustained by a delicate balance of community mindedness and opportunity.

Retention of volunteers is critical to the sustainability of many HIV/AIDS community organisations. But there is a limit to their motivation as they are mainly unemployed people and any efforts to support their own communities detract from their capacities to support their own families. Besides, the stipends received often do little more than cover expenses.

The possibility of steadily training volunteers and offering them opportunities for advancement and marketable skills is key to their retention and replenishment when they move on.

3. Modes of community engagement in HIV prevention

There are significant HIV prevention opportunities in the daily activities of community HIV/AIDS service organisations; for example, home-based care visits, HIV counselling and testing, HIV support and education activities, treatment support programmes and support for vulnerable children. Yet there is much evidence, which will be discussed below, that these supported activities are often not adequately optimised in pursuit of HIV prevention goals.

Local understanding as a starting point

Some community prevention practitioners claim to understand the contexts of risks in their communities without the need for research, by virtue of growing up or living there; and they are able to directly observe the outcomes of their interventions. They do not

need to speculate about change, for on the basis of their observations can say things like

"The attitude has changed quite a lot from negative to positive, one of the reasons being that we have established support groups and HIV prevention teams, which educate people more about HIV. It is respected now more than feared, because people have more information on it." (CBO leader)

Community volunteers have opportunities to observe lifestyle changes or to know when these are not occurring.

In the words of the head of a CBO focused on VCT and education for HIV-positive people, "We could not do one tenth of the work that we do without the local knowledge of our counsellors. They are the first people that tell me, 'Oh, there's a problem there, or there's a problem there, and we need to do something now'."

They see more people taking ART, they know when mothers are adhering to PMTCT protocols, and they witness changes in health related behaviours like drinking. They can also witness or hear of risky sexual behaviour, and they are directly aware when a young person becomes pregnant, for example. They can also see changes that are not sustained when people "*go back to old lifestyle*". They see changes in family attitudes to HIV-positive members, and witness their acceptance back into families following the volunteers' education and support efforts. They witness changing awareness of HIV and attitudes towards people with HIV. Participants discussed how when people find out they are HIV negative, they may become even more careless than before, placing themselves at a higher risk of contracting the disease.

This opportunity to directly experience risk behaviours and prevention responses could be of great value in HIV prevention planning. Access to such information and understanding of contexts of risk within communities is a strong advantage associated with local level responses. While this information is opportunistically used, there is little evidence of attempts to consolidate it in developing more targeted and strategic HIV prevention plans.

Community access and influence

The data revealed use of a wide range of communication channels by community-level organisations. These include: community structures and meetings; community radio stations; community newspapers; community venues; one-on-one and family-level communication; informal conversations in taverns and on taxis; peer group discussions among HIV-positive people; community meetings and workshops; community committees (e.g. clinic committees; youth committees; pension committees; traditional healers association meetings; consultations with traditional leaders; and so on); men only community meetings; and women's associations.

As stated above community-level HIV practitioners have legitimate access to community institutions and communication channels. They also have the local knowledge to know how to communicate with community members in a meaningful and relevant way.

In discussing how HIV/AIDS issues are raised at community level an NGO leader based in an urban area said:

"We definitely know that HIV is a delicate matter, so your approach should cover all the problems incurred in it – it's not an easy matter to talk about, it's very, very delicate, because in almost each family, there is a member. So it touches one, meaning your approach must be very good, not to disturb the meeting."

In addition community practitioners have legitimacy in conducting door to door campaigns, conducting informal prevention conversations with clients in public places, and conducting meetings with smaller groups of elderly people or local traditional healers. They also understand what may be said to whom, and in what way. They know how to approach sensitive topics in appropriate ways, respecting local norms. A CBO leader connected receptivity of people to respectfulness to the audience: "*In order to ensure people are receptive to the prevention messages, it is helpful to be respectful to the audience one is addressing."*

Bridging and linking social capital

In rural areas of the Eastern Cape Province small NGOs and CBO's are seen as being the most active agencies in HIV/AIDS, in an environment where the reach of government programmes is very limited apart from cash grants and health services which are often located some distance away. The only notable government HIV prevention programmes in these areas are public media (radio and television where this is available), condoms distributed in health services and PMTCT programmes. Other services such as VCT are said to be available but are not promoted in facilities.

Civil society organisations are present and visible. In the words of one respondent, they are "in the yards, the centres, the 'location' [townships]. You know that in that street there is a CBO helping in this and this and this. They market themselves to people". Through this capacity they have played an important 'bridging capital' role. They provide linkages and access to resources not directly accessible to communities, and even when they do not provide particular services, they are able to facilitate the provision of such services. For example, home-based care groups in a rural area have partnerships with a town based child abuse centre which they turn to for advice and assistance in dealing with more serious cases of child rights infringements or abuse, and for access to legal aid.

CBOs also help government to take their services to the ground. In prevention this is most notable in PMTCT where government health workers rely on CBO HBC practitioners to support people in following PMTCT protocols, especially in the area of infant feeding. But they also acts as links between pregnant women and PMTCT programmes, ensuring early enrolment in programmes, whereas pregnant women may otherwise only present to health services when they go into labour.

CBOs also help to distribute resources. Supported by the departments of health and social welfare they distribute resources such as HBC materials (e.g. linen savers and dressings for home care) and school uniforms for orphans returning to school. They also distribute condoms although supplies are not always secure. Government departments refer clients to CBOs and require reporting on referred clients although they often do not provide financial assistance for the work. The payoff, apparently, is that government rewards compliance by recommending CBOs for funding. In the words of one respondent: "*So we play the role, but they are abusing us in a way*." The key point is that government uses the community linkages of CBOs as an opportunity to implement their programmes and distribute the resources as they are mandated to do.

In addition to outside linkages CSOs appear to create bridges within communities. The helpful nature of the community was said to be something that could be better drawn on for HIV/AIDS prevention efforts. As one community prevention leader from a rural area said, "*The community itself is very enabling, which is something we can exploit in terms of using more community members to help with HIV prevention.*" CSOs mostly work

within communities bringing different structures and groupings together, bringing churches together through combined projects, involving local businesses in supporting HIV/AIDS prevention and support, and creating linkages between government departments and people who need their services. They also create communication structures within communities.

Conveying HIV/AIDS information to communities is an area of contribution for community-based organisations, but has not been researched or quantified in any meaningful way; at least in sub-Saharan Africa. That it exists and is critical to community responses to HIV/AIDS is plain to see. It is also undeniable that it has developed and is partly sustained by funding, although it is largely a by-product of attempts to fund CBOs to provide services. The kinds of support needed to optimise its value and to assist it to grow should be the subject of much more serious consideration than it has been given in planning of HIV/AIDS responses.

HIV/AIDS awareness

The bulk of efforts of community-level organisations seems to be oriented on awareness building events that may include: talks, plays, talent shows, choir competitions; debates, sports tournaments, street parades, community radio talk-shows, local newspapers, poster campaigns, and much more.

Through such opportunities efforts are made to educate in ways that are understandable and acceptable to communities. HIV/AIDS terminology is translated into everyday language and efforts are made to halt the use of harmful and stigmatising language.

Beyond the opportunity to reach community members, the success of these HIV awareness type of events is questionable. There was some suspicion expressed by HIV prevention leaders about the achievements of community HIV/AIDS awareness events. For instance, one CBO leader said that her organisation had discontinued attending annual community sports events. She explained:

> *"What we tend to find is that during the awarding of trophies it's where we are going to talk about HIV, HIV prevention, and the pandemic itself – but we find that these players are not sitting and listening, they are roaming around waiting for the pub nearby. So it happened, and then we tried to change it, whereby we sanctioned that no-one must leave, it ended up being 'we are forcing them' to listen to us."*

This must come with some risk that too much low-grade and incessant background HIV exposure may dull people to the urgency of need to respond to HIV/AIDS.

There was also evidence of attempts in most communities to communicate with specific audiences. Our data included efforts to reach the following otherwise difficult to reach groupings: the elderly; tribal meetings of headmen and chiefs; traditional health practitioners; sex workers; vulnerable children; and people with HIV.

Gatherings of such groups for other purposes are seen as an opportunity to communicate about HIV/AIDS. There is evidence that such opportunistic efforts at promoting HIV awareness have sometimes been negatively perceived by groups gathered for other purposes. On the other hand, many of these audiences are not otherwise easy to reach and the events tend to rupture silences and get people discussing HIV/AIDS.

But in either instance – community events or community group gatherings – questions must be raised about what is achieved, and those involved in conducting these interventions are not able to describe outcomes of their efforts in a convincing way; other

than to describe who was reached and how.

Prevention awareness and messages appear to be largely adopted from national and international programmes, and even the slogans and t-shirts in evidence reflect this. In short, whereas there was much evidence of creativity in reaching people, the content lacks local adaptation which might be hoped for in community based prevention responses.

While there certainly are exceptions in other parts of the country, in the twenty organisations from the Eastern Cape involved in the research there was no mention of use of behaviour change models or life-skills education modules in conceiving or talking about such awareness raising events. Even if skilled drama-in-education projects provide only once-off interventions, albeit using highly innovative and expert facilitation methods, it does not necessarily lead to behaviour change. Much more concerted and strategically planned interventions are needed to halt new HIV infections.

Some CBO leaders spoke of the need for better targeted interventions such as door-to-door visits and 'informal talks' in sites such as taverns. They felt that these allow for much more focused and tailored engagement of people in thinking about their own HIV prevention needs and responses. But these are time-consuming and large numbers of people cannot be reached in this way. –

The above raises troubling questions about the adequacy of community HIV prevention priorities and methods for achieving them. In all of the data referred to in this study only that from Zimbabwe showed evidence of a strategic – and strategically developed – complex of HIV prevention responses at community level. This involved situational review and analysis, delegation of tasks and downward mobilisation of communities through civil society organisations and local coordinating bodies, and a broad combination of prevention approaches.

In summary, mostly organisations are oriented on broad prevention messages, and their innovations are largely around method of delivery as opposed to honing and selecting messages according to the r needs of people in particular types of context. Whereas it is important to create opportunities for community-level HIV communication and to provide information at this level, the real benefits of communication come to fruition in the context of: individual appraisal of risk and prevention decision making; communication between sexual partners; care of vulnerable children; exercising reproductive health choices; undergoing HIV testing and follow-up counselling, and so on. No amount of messages about 'sticking to one partner', avoiding concurrent partners, avoiding intergenerational sex, using condoms and abstaining from sex will work, unless the communication involves people assessing their own HIV exposure risk and prevention options and this is not likely to happen in public space. Communication focuses on outcome level messages (behaviours that are desired), rather than the 'means whereby' outcomes are achieved. Focusing on the means whereby involves understanding of the component processes that go into building an HIV prevention environment and HIV prevention decision spaces in the lives of individuals.

Home-based care

Participants providing home-based care services recognised their opportunities to educate family members about HIV prevention. They see care and support to sick clients as indirectly supporting prevention. If a person with HIV is well taken care of and returns to participation in everyday life as before, people in the community see that it is possible to

live a ‘normal’ life with HIV. This promotes less anxiety and greater openness about HIV; although in reality the links between HIV testing and prevention are quite tenuous.

Carers tend not to realise their opportunities to practice prevention *within* their work or primary mission. Their workspace affords a prime entry point for HIV prevention work that is closed to others, including those working as HIV prevention educators. Carers have ongoing contact with HIV-positive clients and this provides an entry point into counselling them in HIV prevention and promoting prevention in sero-discordant couples. They are trained to support women to follow PMTCT protocols and do this with pregnant women, but they have more primary PMTCT opportunities that are not pursued; notably family planning counselling for HIV-positive couples. Working in homesteads they have opportunities to engage in ongoing ways with young people who are socially vulnerable and to assist them through counselling and life-skills coaching. The work of carers also provides opportunities to work closely with people otherwise difficult to reach in communication campaigns

These opportunities are largely not brought to fruition. For this to occur home carers would need additional training. They would need to be competent counsellors. They would need to understand prevention options for sero-discordant couples and be in position to promote and guide family planning. They would need to understand ways of supporting behavioural prevention decision making in young people. They would also need to develop stronger linkages between VCT centres and home-based care. They would need to secure linkages between support and care programmes for orphans and vulnerable children and prevention programmes or initiatives for children and young people. Approaches based on better teamwork between agencies would likely make a positive contribution, but would not substitute for the need for carers to do prevention work within their own primary areas of work.

HIV counselling and testing

Community-level voluntary counselling and testing services are mainly provided at government clinics, although there are some CSOs that provide such services. CSOs range from multi-site service providers working on a social franchise basis to single community organisations (CBOs). CSO services are generally more mobile and able to get closer to where people live, as clinics are often some kilometres away and people need to pay for transport. CSOs with mobile services visit outlying areas and can conduct their work on demand at workplaces – generally with more flexibility and less bureaucracy than is the case with government services.

It is notable that within the communities covered in this research, services provided by CSOs appear to have been used by a broader spectrum of community members than have clinic services. Men in particular tend to avoid clinics, and the walk-in, more client-oriented services of CSOs have been favoured in one small town in the study, which conducts more non-medical tests than all of the other facilities (more than six clinics) combined. They maintain that preferences for their services are stated by clients as involving greater confidentiality (away from the public eye at clinics where it is evident that going into a particular room means an HIV test) and shorter waiting times.

In general, respondents involved in providing VCT services speak of the need and value of pre- and post-test counselling for both negative and positive outcomes. But data from participation in training workshops run by CADRE revealed that it was apparent that those who conduct these services do so in somewhat blind belief that they are conducting

HIV prevention by offering VCT. The twenty to thirty minute procedures (sometimes as little as three minutes for HIV-negative outcomes) that are followed cannot reasonably be considered to secure prevention outcomes. Organisations and their funders often 'count' VCT as a prevention intervention, but questions must be raised about this assumption.

The literature is equivocal on the efficacy of VCT as an HIV prevention method, and even more so

Knowing one's own and one's partner's status is important in the interest of introducing HIV prevention, but is not the end point of the HIV prevention results-chain. It is what is done in the VCT counselling encounter that matters, and specifically how it is translated into prevention outcomes. VCT outputs are often pursued without linkages to the kinds of supports that are necessary to ensure that the method reaches its destination as prevention outcome.

VCT counsellors need to be trained in all aspects of HIV prevention support, not simply in pre- and post-test counselling. VCT must always be linked to post-test education and support programmes for HIV-positive people with a focus on prevention.

Perhaps in this area more than any other the opportunity and intense programme efforts are not made good of. The VCT entry point requires much more than VCT and there are very few facilities that provide these outside of the civil society sector. Much stronger linkages need to be systematically built between government and civil society service providers and community prevention, care and support initiatives.

Support for people living with HIV

National HIV prevention programmes have almost exclusively promoted individuals protecting themselves from HIV infection. Positive prevention is practiced by people who are already infected and it is oriented to preventing passing the virus on to others. Engagement of people with HIV in prevention is now recognised as important but remains an overlooked element of HIV prevention programming at national as well as community levels.

The approach requires a supportive social and health services environment that is conducive to people wanting to know their status and being motivated to practice prevention.

A number of respondents spontaneously mentioned that they were HIV-positive and the meaning that this had for their involvement in HIV prevention. In the words of one female CBO leader:

> *"I didn't know my husband had HIV, then he passed away in 2001. I accompanied him to hospital, and the results came, then when we got the results. Ey, I was touched... because I know, if there's HIV, then I also got HIV. From 2001 to 2004 I was afraid to test, because I was afraid to check my status. I live, but this thing was on my mind – but one day I was thinking that 'if I'm staying not testing, my life's gonna end' . I went to hospital then I check my status, then I've got positive, then, ey! I'm not crying, at that time – I phoned my sister, brother, my families, and they came to me, and counselled me that they know the status of my husband, but they did not push me to test, because they didn't know how I would feel, myself. Then, I was very sick at that time: I got TB, and I treated my TB, finished. And this year I heard about the organisation in my local areas so I went to there and talked and said 'I want to join you because in my location I see the young people are dying with HIV, and I want to*

help.' I'm talking about myself when I talk to those young people, I would tell them 'look, you will still live more years if you admit, look at me, you see when I'm sick – you call the ambulance, cars to take me to hospital, but now, I'm alright'. I want to convince them that they will still have long life if they go to the clinics and test themselves, and go afterfor treatment. So I decided to join an NGO. It came from me."

However, the outcome is usually not as positive. HIV support group respondents said that HIV-positive persons are commonly ostracized in their communities in the Eastern Cape Province. One respondent said:

"When there is a funeral or ceremony where people share food they will normally skip someone who they know has the status. This is accepted by everyone in the village. So people, once they get the status, they don't want to disclose because they know the treatment that will follow."

People with HIV are also often labelled sexually promiscuous and shame stalks them, leading to secrecy and denial. Community members give stigmatising 'names' to HIV/AIDS. This reinforces secrecy. Such experiences were cited as major barriers to those infected becoming more positive about their condition and being motivated to prevent infection to others.

This is recognised by community organisations as problematic and there are efforts even in rural areas to counteract it; particularly in the form of support groups for HIV-positive people. The term 'living positively' appears to have found a foothold at community level and support and education programmes are seen as needed; although HIV support was seldom spoken about in terms of HIV prevention. 'Positive living' tends to be limited to assisting people to deal with stigma, support for disclosing HIV-positive status, educating people about the importance of maintaining a healthy diet and leading health lifestyles, and treatment literacy education and support for adhering to treatment. Prevention was barely spoken about.

One CBO included in the study focuses on VCT services and supporting people with HIV, but has a very 'by-the-way' focus on HIV prevention. People with HIV-positive VCT outcomes are largely counselled and supported towards managing their own health rather than being seen as prime candidates for supporting HIV prevention.

It was notable that there was very little emphasis on the avoidance of unwanted pregnancy as a programmatic focus in 'positive living' initiatives. PMTCT was only a marginal focus for most of the respondents; and was seen as being the business of clinics rather than community prevention initiatives. However, PMTCT is addressed by home-based carers who identify pregnant women and advise them to go to clinics for VCT and to engage in PMTCT if necessary. When this is the case home-based carers see it as their responsibility to follow up on pregnant mothers to see if they tested positive, and if so, to ensure that they receive prophylactic ARVs. They also support them in following preventive feeding protocols.

Community organisations provide opportunities for people to disclose their status publically. They have worked to situate AIDS as a 'normal' disease that can be lived with and managed. Some home-based carers, support group members and prevention team members in the rural study community openly disclose their HIV-positive status, and try to be role-models for living positively in social environments where there is little motivation for being open about one's status. Programmes to encourage and support people living with HIV have had generally poor uptake with people often reluctant to

attend group meetings, feeling that there is little to be gained from them.

A member of a support group in a resource poor area expressed negative sentiments about support group meetings:

> *"So in a way people want to gain something out of it rather than going about it saying 'I'm living positively' but at the end of the day you can't even feed yourself. That's the whole negativity about being positive. You're already being outcast and now you have to go out of your house being positive and at the end of the day you don't come back with anything. It doesn't motivate you to be positive. If there was more to be gained from being positive, surely more people would tend to live more positively – if they can see results."*

Good outcomes to being open about one's HIV status are by no means assured. An Eastern Cape 'ambassador' of HIV/AIDS and his wife, both of whom openly disclosed their status, and who talked freely at local events and over the radio about being HIV-positive , the need to disclose, and the importance of not re-infecting one another, were silenced by some people who "*read him negatively*". "*They went to his house with guns, they wanted to kill him*." Participants from the HIV support group said that this "*champion of HIV/AIDS*" subsequently attempted suicide and commented that he lost his stature by crying publically. They reported that since then the community has been "*losing people willing to disclose. No person wants to die, or no person wants to be stigmatised*". Participants were careful not to mention the names of the couple – as if their status has become a secret again.

A further dimension of 'positive prevention' is well-managed ART. It has now been established that when viral load becomes undetectable the chances of infecting others is negligible and to this extent ART is an HIV prevention method. However, this prevention information was not raised by respondents as something they address in their work at community level where there appears to be little or no emphasis on promoting linkages between treatment and prevention.

In summary, the need to create a more positive environment for people with HIV is recognised as important by community organisations, but there has been limited buy-in. Support group programmes need to be strengthened, more resources need to be fuelled towards HIV positive people, and the prevention possibilities need to be promoted. This needs to begin with guidance and training in promoting HIV prevention among those who know that they are HIV-positive.

Income generation as an avenue for HIV prevention

It was often said or implied by respondents that poverty breeds fatalism or at least a sense of accepting existing conditions as inevitable and unchangeable. It was said that

> *"Kids we have here who come from poor homes say, 'What is the point whether I prevent? What difference does it make whether I'm HIV-positive? There's no future.' So income generating activities – how to get out of poverty - are the kinds of things that we also need to think about when we talk about prevention." (CBO staff member, small town)*

In Tanzania we found evidence of small-loans used to support income generating projects, with success measured by evidence of multiple small ventures, high levels of repaid loans, and maintenance of the loan fund over a number of years (Kelly, 2008). In this context the HIV prevention gains were through reducing the likelihood that

unsupported mothers and orphaned young people would engage in sex work.

Whereas there is some evidence from South Africa that income generating activities supported by small loans can improve the livelihoods and quality of life of people with HIV and their families (Pronyk et al. 2006) there was limited evidence in the current study of the use of income generating activities in promoting HIV/AIDS responses; and none that point to easy wins in terms of HIV prevention.

One example is an NGO-led programme oriented on HIV prevention that conducts a cooperative farming initiative spanning five villages. The meetings of this organisation always include HIV/AIDS communication and training relevant to prevention and impact mitigation. The strategy is that information and life-skills will diffuse from these motivated and enthusiastic participants drawn by income generating opportunities to people in their communities; and it is also hoped that income generation provides some form of protection from HIV risk, although why this is likely to be the case was not really articulated.

A more comprehensive example is a rural programme combining crafts and HIV/AIDS response. This programme has developed significant income generating capacity by bringing together the expertise of designers and local crafters in creating internationally marketable products. The project is also the hub of a leading treatment and prevention initiative. It has created a positive community spirit in response to both HIV and the lack of economic activity in the area. The project is led by a highly talented person who is both a medical doctor and an artist. This means that it is likely not replicable and if anything the programme points to the immense challenges of making community projects like these viable and sustainable.

If income generation projects were viable on a wide scale it is likely there would not be a need to promote them, because they would be part of the general economic environment. Challenges of developing and maintaining viable income generating projects given the lack of background skills on the part of CSO staff and volunteers means that whereas the idea of generating income is a draw-card, the likelihood of this yielding a strong return on investment is limited. The strongest links between economic gain and HIV prevention arise from opportunities the community HIV/AIDS organisations offer for generating income for volunteers and staff, gaining skills and developing work experience. This allows community members to support HIV prevention programmes as well as gain some chance of engaging in gainful work.

Conclusions

Community level HIV/AIDS workers have rich opportunities to pursue prevention goals through: excellent local knowledge; good community access and credibility; linkages within and beyond communities; and opportunities to promote HIV prevention in the course of home-based care, VCT and HIV support. However, these opportunities are not seized on to the extent that they could and should be. This is mostly because prevention practitioners at community level are not sufficiently knowledgeable about how to achieve HIV prevention in targeted ways and to selectively use the range of prevention approaches available. The entry points are open but they are not used to good effect.

4. Cultural, religious and symbolic approaches to HIV prevention

Tradition and culture in HIV prevention

There has been much said about the need to respect cultural practices and engage cultural entities in dealing with HIV/AIDS. However, the picture that emerges on the ground showed that opportunities are limited for adapting deep cultural practices to the needs of HIV prevention.

We spoke with young men from a rural area, most of who had undergone traditional circumcision. The spoke of the use of the same' spear' to circumcise around fourteen initiates, most of who had already been sexually active and could have been HIV infected. Yet, because Xhosas seek to minimise modern influence in such traditions, the young men felt it would be difficult to change the initiation practice at community level. Circumcision practice is deeply respected and guarded in this culture and it does not easily entertain 'other business'. The manner and context of its practice is too deeply connected to ideas of male identity to be fundamentally reshaped in the interest of HIV prevention; at least in the deep rural areas we visited.

Other cultural practices are more a matter of 'the way we do things'than long-standing tradition, and are more malleable. A CBO leader from a rural area spoke of a practice which is common after undergoing circumcision: having unprotected sex with someone who is not your regular partner after returning from circumcision school. Although related to circumcision this practice is not culturally 'protected' or sanctioned behaviour in the cultural sense. He said: "*We try to stop that practise."* This is not resisted by the guardians of circumcision traditions, although as indicated previously, unlike the relatively impenetrable and deeper cultural practices around circumcision.

On a more receptive note we found prevention work aimed at engaging traditional healers in HIV education and we encountered a project aimed at developing referral systems between medical services and traditional healing services with the aim of improving diagnosis and treatment in keeping with standards of medical science and practice. It was also evident that traditional leaders had been brought to the point of being supportive of HIV/AIDS projects in their area, and HIV/AIDS CBOs and NGOs were embedded in deep rural and tribal areas with the authority of traditional chiefs.

We found some use of local dance and music cultures adapted to serve HIV prevention purposes, but really only as channels of communication for HIV/AIDS messages.

'Culture' was described by one respondent as a way of holding on to old ideas and resisting new ones. Saying that something is not in 'our culture' is not necessarily related to specific and defined cultural practices, and it was reported to be quite a common utterance by community members in deeper rural areas where there are lower levels of external HIV/AIDS NGO presence. It is often said, for example, that it is not in Xhosa culture to openly discuss sex.

A leader of a city-based CBO described how his organisation works against 'culture' used in this sense:

> *"And what you find is when it comes to question sessions… people do question. There was a barrier - when we talk about HIV, we talk about sex - and you see everybody's looking down. But over time, when people get to interact about these things, we find that when the session is finished there are small groups outside the meeting place discussing what we were saying."*

CBOs have the legitimacy as community structures to introduce debates about issues that are seldom spoken about and that are sensitive. They have raised discussions about the role of men in spreading HIV, challenged people to talk more openly about sex, encouraged HIV disclosure, and spoken out against the secrecy and silence around

HIV/AIDS. It is in these areas of everyday culture that they have most exercised their role as advocates for HIV prevention.

Faith responses

Christianity is the predominant religion in the study sites, and Christian churches and other institutions are present in all communities covered in the study, including rural areas.

Respondents tended to speak negatively about the involvement of Christian institutions in HIV prevention. As one respondent explained about one of the major church denominations:

> *"The [name of church], has got a policy, it has got dedicated funding. HIV and AIDS is a fundamental part of its mission, and its senate has said that AIDS is the biggest challenge for the church. So, I think the Church is quite mobilised, already, conceptually. Now it's a question of getting the proper application…but unfortunately interventions are poorly planned, so [the Church has] never functioned to its best."*

There was a general feeling that whereas churches are 'good at' caring, their HIV prevention responses had not been helpful. A respondent remarked "*We want to get away from the churches…some churches are still not comfortable with even discussing HIV and AIDS.*"

These responses do not reflect the scale of commitment of churches to HIV/AIDS in South Africa or the continent; and they particularly reflect responses to HIV prevention needs rather than HIV/AIDS care and support or treatment needs.

There was little said by respondents about innovative prevention responses which present new opportunities for HIV prevention. One exception was an effort on the part of the Zimbabwe the Heads of Christian Denominations, which introduced a programme to promote HIV counselling and testing as part of marriage preparation. Although there are reported capacity and quality problems associated with implementation, it is a notable attempt to extend the church's HIV prevention role using public health principles, while remaining true to the church's primary mandate of supporting HIV prevention through faithful relationships.

Beyond this it was felt whereas churches provide good opportunities to reach people – given the numbers of people who attend and 'believe in church' and their proximity to people – their effect at the level of prevention was not notable.

Symbolic and psychological aids to HIV prevention

The research has brought to the fore a number of 'assets' which are essentially symbolic aids to HIV prevention and that draw on nascent individual and community attitudes.

The following illustrates a complex mix of values, emotions, loyalties and inspiration that together shaped an NGO leader. Asked how she first heard about HIV/AIDS, she responded:

> *"From someone who was HIV-positive and her organisation, we are calling Nomawethu – it is not her real name. She was not my friend. She was older than me, and just called me to make [start up] this organisation, to prevent and take care of their children when they are dying. She educated me about the HIV/AIDS, and in 2003 she passed away. Then I continued to make prevention and make a network with other*

NGO's, such as an intersectional forum for NGO's [in a city]. Then I learned how to run programmes of HIV/AIDS."

Another participant added:

"I think what drives her to be in the HIV programmes until now, is the way she sees Nomawethu before, and the time when Nomawethu was struggling with her life, until her death. So I think the period with Nomawethu gave her the strength, and then she had in mind that 'I will push this until such time I can't push it anymore' – just for the sake of Nomawethu, because she chose to lead and to educate the community, and stress the prevention methods, and please, take care of the orphans who are the results of the HIV and AIDS: I think that's what drives her up to now.. It's the loyalty... and the passion to serve, because of the community."

Embedded in this story are a number of symbolic and psychological attributes that support her engagement in HIV/AIDS responses including prevention. These and others attributes identified in the research are:

The value of caring: Both home-based carers and those involved in supporting young people affected by HIV/AIDS reported being moved by the value of care. They spoke of personal commitments to serve their communities which had little to do with their own needs. They reported making personal financial and career sacrifices to support people who they had not previously been closely related too. It was noted that levels of care by community volunteers for people affected by HIV/AIDS exceed the kind of care that is generally available for sick or destitute people. Questioned about why she does this a home-based carer explained that she is motivated and inspired by what she does simply because she loves to care for people.

Being a man: Young men discussed how males can be encouraged to take the initiative to test for HIV in a relationship, and then have the authority to ask their girlfriends to test. The idea of being 'a man', of having responsibility and taking a leadership in a relationship, may be inconsistent with egalitarian conceptions of relationships, but within the particular culture (Xhosa) in question, this attribute was said to be useful in HIV prevention.

This raises a well known quandary in engaging cultural images for social change. Embedded in the image of the man as the leader in a relationship, is the possibility of domination of women by male partners – the seeds of which may grow to overshadow women's rights.

A more positive and less questionable symbolic aid to men's involvement is the image of the father. Focus group discussions around prevention of mother to child transmission showed that father's commitments to the wellbeing of their children and grandchildren involve a strong invocation to care and protect. This has largely not been drawn on in involving men in supporting their partners or children to engage in PMTCT. There is, however, a national South African campaign called 'Brothers for Life' which aims to appeal to men in a general way to be supportive, caring and communicative.

Pride and respect: Support group members and prevention team members who receive trainings, skills and knowledge as a result of being involved in prevention work take pride in these accomplishments, and when they are respected and appreciated for their efforts and assistance, this reinforces their motivation to work as volunteers.

The idea of the family: A rural CBO worker explained that she has to adopt diversionary tactics in supporting families. She explained that "One strategy is to talk about family life

and promoting family life, because you find that the affected families need information on HIV and AIDS, but at the same time they don't want it to be known that they have a person who is HIV-positive." By approaching the problem from the point of view of supporting the family, and by promoting the project as one which is supportive of families rather than dealing with HIV/AIDS, a more acceptable and positive context of engagement is created.

Families were seen by some participants as being under-utilized resources for prevention. The involvement of fathers in instilling responsibility for sexual behaviour in sons who are undergoing initiation was one example offered. There are likely many underutilised opportunities embedded in the idea of the family – including the care of older siblings for younger siblings.

Conclusions

It was found that cultural and religious practices and institutions provide some entry points to HIV prevention. However, their contribution to HIV prevention is limited, sometimes contested and difficult terrain on which to conduct HIV prevention.

The research revealed a range of symbolic 'assets' which are used to draw people into HIV prevention, reflecting deeply held values and aspirations at individual and community attitudes.

5. Funding and support for community-level responses

Availability of funds

Organisations expend a great deal of effort raising funds to keep their work going, and they appear mostly to be in perpetual funding crises; just getting by from month to month.

The viability of many of these organisations seems tenuous, at least regarding funding. They appear to survive from project to project, often with one source of limited funding that takes care of basic costs. But this is often not secured beyond annual funding cycles and many organisations that are not supported by an umbrella organisation are in perpetual crisis mode with regard to funds. The consequence is that they are not able to plan or strengthen their efforts. Many of these organisations survive rather than thrive.

Sources of funding and support

There is no national funding infrastructure, nor systematised civil society funding mechanisms specifically for HIV/AIDS organisations.

Organisations that provide well defined and limited services – for example, community support for vulnerable children, peer education or HIV counselling and testing – are often tempted to undertake new forms of work when funding opportunities appear. But there is risk that when such new funding ends the programme continues (for example, vulnerable families still look to the CSO for support and the programme has no option but to try to provide the same) and this creates organisations that are too spread and less able to meet community expectations and contractual commitments. A strategic decision facing any community organisation is whether to opt for focused core-skills and functions that are recognised and supported as a limited *part* of community HIV/AIDS responses, or to be

more comprehensive and openly responsive to community needs. Such decisions are often not made from a strategic vantage point, but as a reaction to immediate demand and opportunity. This does not bode well for the long term security of such organisations, as they are typically over-extended in their range of commitments.

Funding is often tied to delivery of specific services. This may be appropriate for small organisations that do not have the capacity to do much more than plan around specific deliverables. But this kind of funding is limiting for more established organisations that could lead local level HIV prevention coalitions and develop longer term strategies involving local collaboration.

Another outcome of 'prescribed output' in many respects counteracts the likelihood of communities pursuing truly local options for prevention. The predominant focus of prevention remains oriented to 'ABC' (abstain, be faithful, condomise). In the words of a home-based carer from a rural area:

> *"There seems to be a minute role, or one track mind in terms of thinking of prevention because of the rural areas mentality of the people. It's either condoms or abstinence."*

The unpredictability of funding, chronic funding shortfalls and funding tied to specific services delivery with limited discretionary components create a context of organisational insecurity and instability. CSOs do little more than plan within funding cycles. It is also notable that the opportunity costs of securing funding are significant and absorb much of the time of the senior staff in organisations who are best placed to develop longer-term visions and strategic plans.

Smaller CSO organisations can see the need to grow to a scale where they have sufficient infrastructure and programme management expertise to be able to attract the interest of larger funding programmes. There are a number of funding opportunities for smaller programmes, most notably the national lottery, but whereas this source of funding may provide a lifeline to organisations it cannot be used as foundation for long-term planning. Nonetheless, it selects out those organisations with sufficient determination and committed management from those that are not likely to survive in the long term. The continued existence of CBOs is proof of their durability and commitment. There are also a number of organisations focused on assisting CBOs to develop and register; and which provide start-up funding and support to the point where they are able to provide basic services and function as self-standing organisations.

Each CSO has a unique story of its own origin, which usually can be traced back to a small group of inspired individuals, or sometimes one person moved to respond to community needs. As these organisations develop they are increasingly shaped by legislative requirements of non-profit organisations, requirements of funders and the expectations of their constituencies. But the role of individuals in organisations, the function of governing bodies and the organisational cultures that emerge, tend to be idiosyncratic rather than standard. It is a challenge to balance this with the more standard requirements of funders.

Government funding and support

One CBO leader from a rural town explained that she had devoted herself for nine years to serving her community through an HIV/AIDS organisation without any real help from Government. She felt that government expects CSOs to contribute to its campaigns without providing support or funding. She and other respondents in the focus group bemoaned the fact that although they provide efficient and much needed professional

services, for example in home-based care, they do so with minimal recognition by government and funders. They felt that there was something "wrong with the system" when they are called on to support government programmes of action without due compensation or other support.

We found some evidence of progress towards government engagement with community-level prevention responses in the linkages of at least three government departments to community organisations. This took the form of stipends for HBC volunteers and the supply of commodities. A pilot project of the Department of Social Development facilitates support in the form of organisational development training and stipends for home-based carers to CSOs in the area of community and home-based care. The Eastern Cape Department of Agriculture provides seeds for community gardens, which supports CBO efforts to secure nutrition for households affected by HIV/AIDS.

However, CSO leaders reported that such efforts are typically provided 'once-off' or inconsistently, and with little follow-up or attempt to develop longer-term services through these organisations, or to assess the quality and effectiveness of their services. Even where there have been longer-term relationships between government and civil society organisations, government support has proved unreliable and unpredictable.

A case in point was a 'men in partnership against AIDS' project introduced by a provincial government health department to enthusiastic reception by community organisations. Specific promises of support and follow-up were made but these did not materialise and community-level organisations involved were never informed about the apparent abandonment of the initiative.

Training, supervision and the presence of government representatives on the ground is rare at project sites. Participants were of the opinion that if representatives from the government departments were to put in an appearance at HIV/AIDS education interventions in community education initiatives, it would add more weight and authority to the work of CBOs.

Participants complained about the poor organisation and commitment of government officials. As an example a participant spoke of the efforts of a particular municipality to establish a local AIDS council headed by the Department of Health at local level. Despite being well resourced and unable to spend a budget provided by local government, mechanisms for supporting travel costs of participants to municipal meetings of this kind (less than the equivalent of US$ 3) proved to be problematic, as was the organisation of food and refreshments. The Department's facilitator/co-ordinator was consistently very late for meetings and management of the process, which was well subscribed to by local actors, eroded confidence in the entire initiative. It was felt that whereas Government expects and invites the participation and cooperation of CBOs there is much evidence of poor investment and commitment on the part of government itself.

There are certainly some government officials who are highly dedicated and there is much evidence of government initiatives to engage community organisations. But at some level the commitment to the vision of engagement with extra-governmental organisations is not firmly established and accountability at this level is decidedly poor.

There is need for a clear declaration of government commitment to the idea of using civil society organisations to assist in fulfilling government's commitment to service delivery. At the moment government's support is limited to project level funding and it lacks clear commitments at both policy and programme levels. There is no real foundation for monitoring and accountability at this level. A six-country study of funding and support

for HIV/AIDS civil society organisations in Southern Africa came to similar conclusions (Birdsall & Kelly, 2007).

Funding tied to capacity building

There is a range of programmes aimed at supporting CSOs through funding as well as capacity building. Funding and capacity building support are sometimes combined by small-grant associations, NGOs and companies focused on supporting new organisations to grow around project funding. The two main variants in capacity building are attempts aimed at assisting projects to become independent non-profit organisations (NPOs) registered under the Department of Social Development, and capacity building focused on developing particular skills. Skills training often occurs when CBOs participate in a larger funded programme, often conducted by an international NGO or company, usually with a block international grant; for example, from PEPFAR or the Global Fund.

Funded community based organisations tend to neglect internal development activities through a focus on the demands of delivering key prescribed outputs. At the same time managers are preoccupied with funding and the administration of the organisations is often neglected.

By contrast a need for linking seed-funding and organisational support was reflected in the enthusiasm of a group of young men engaged in HIV prevention in rural areas. They discussed their vision of becoming an organised and funded body. They expressed the need for a project budget that is determined by their needs. They have specific requirements in terms of commodities and equipment needed to achieve their goals and they say that although they are constituted as a prevention group they are unable to fulfil their vision because of problems of marketing, transport, coordination of prevention communication events and so on. A group member went on to say:

> *"If we were to form a body that is funded with transport and employed a couple of individuals... everyone would be divided into his or her own department. Some would be doing dramas, some doing management of sounds, some doing awareness speeches. It is about being able to mobilize yourself around the country or villages with sound equipment and everything you need to do an awareness program."*

There is little reason to think that with funding this group would be effective, that it would manage itself adequately and spend its resources wisely; or that it would deliver what it hopes to. But the example serves to point to the need for forms of funding that bring together organisational development support with structured and incremental funding.

Some models are emerging that tie funding to capacity building and that try to fund capacity building of organisations for delivering services at appropriate levels. A good example among these is Ikhala Trust, a small grant-making facility that operates as a micro-fund for existing community based organizations operating within the Eastern Cape Province. The Trust assesses and builds on existing community 'assets' and targets smaller organisations which tend to be overlooked by donors. It not only provides seed funds, but assists in building organizational management capacity and linkages. This approach raises the possibility of intermediary civil society organisations or networks raising block grants from donor agencies including government. The block grants are then disbursed as multiple small grants to successful community based organizations alongside assistance to promote their efficiency and effectiveness.

Competition for funding and clients

There was some evidence of competition for funding between organisations working in the same field – for example, HIV support – and this was spoken about in negative terms. In sharp contrast to most other fields of endeavour where competition is seen as healthy, the negative view of competition in the sector is understandable given that most of these organisations are registered non-profit organisations.

But in reality CSOs sometimes pursue opportunities and exercise leadership in ways that reflect competitiveness. Some concerns were expressed about organisations working in the same field competing with each other in terms of where they work or the populations they target.

The threat of large scale international programmes

There is increasing evidence of large-scale, multi-community programmes becoming active in communities. These are often supported by grants from PEPFAR and the Global Fund.

These programmes usually involve implementation of a model of comprehensive community responses but they are sometimes quite specific in focus; for example, focusing on OVCs or HBC. They are sometimes implemented by international non-profit companies but also international consulting companies; and it is also quite common for the non-profit organisations to register in the country and call themselves *national* NGOs despite remaining tied to their international parent organisations. Their work often involves sub-granting to community organisations who implement programmes, but it may involve direct implementation of services.

There is much disaffection about the presence of international development agencies among national CSOs, although there is muted expression of this outside of civil society network meetings, for fear of biting the hand that feeds. Some of the problems identified have been documented (Kelly & Birdsall, 2007; Kelly, 2008). It is interesting to see this development beginning in South Africa for the first time under the USAID PEPFAR programme.

In one of the communities in the present study, an international NPO is establishing a comprehensive treatment, care and prevention organisation in a municipality without prior consultation with organisations that have long histories of working within the area. This initiative may have involved consultation with government health officials, but local CSOs were only consulted after the decision to establish the programme had been announced. The government treatment centre welcomes the development as it has reached full-capacity to manage demand for its services and the new programme comes fully stocked with medical personnel, a pharmacist and other support staff. However, local CSOs are threatened by the prospect of this external organisation poaching their staff and possibly volunteers – and with good cause since the salaries offered are considerably higher than those which local CSOs can afford. There is also uncertainty about how the presence of the new international organisation will affect funding to local organisations and there are fears that the relevance of these truly local organisations will be tested.

That there was need for a more systematic and integrated system is quite apparent, but the model of establishing national programmes run by international organisations at local level is questionable. It does not bode well for this community's internal and long-term

responses to HIV/AIDS, although it will certainly help to alleviate backlogs in the short-term.

Conclusions

The funding situation for community level HIV prevention programmes is not conducive to effective planning and consistent service provision. In the absence of some form of national programme for supporting HIV prevention at community-level there appears to be little prospect for a more systematic, collaborative and effective approaches to prevention at community level. The skills and capacities of community organisations are also not likely to significantly improve in the current situation which appears to be beset by survival concerns rather than growth and improvement.

6. Strategic management

Monitoring and evaluation

The idea that monitoring and evaluation (M&E) is important has been strongly communicated to community organisations through funders requiring M&E strategies, outcome indicators and the like. Yet their understanding of the value of M&E practice appears to be limited to reporting of output level data to funders as required.

It was apparent in the HIV prevention trainings that while most programme leaders had heard of results based management, there was little evidence of them using its principles to an appreciable degree. Instead of an ongoing striving towards 'outcomes', results tend to end with successfully delivered 'outputs' in keeping with funder expectations.

The overall finding is that community-level responses are not strategically developed or thought through in terms of long term goals, strategies and objectives. The organisational and work culture of many of these organisations appears to be in perpetual crisis mode of funding and patchwork programme work, which is severely limited in planning and execution by unpredictability of funding, and by programme leaders who are not adequately skilled in management and strategic planning.

CSOs are acquainted with funder reporting requirements, which they almost universally bemoan, but accept as part of the territory.

They are sometimes cynical of data gathering efforts when they battle to obtain in return from government sources and funders, basic information about the local epidemiology of HIV or coverage of services. They wonder what happens to the data they submit and why valuable information about local responses is not generated from the quantities of data submitted to funders and sometimes to government departments.

It appears that the fairly optimistic picture painted in the literature review around HIV support and care is not duplicated on the ground in the area of HIV prevention. This may HIV prevention is more complex, requires more careful matching of methods and target groups, involves more assumptions and is harder to assess at the outcome and impact levels.

It should also be noted, although it was barely mentioned by respondents, that both in South Africa and the sub-continent there are a number of civil society networks which focus on coordination of civil society responses. There are also regional networks. In some countries (Kelly & Birdsall, 2007) there is competition between these networks and

the civil society sector is far from being unified or oriented on common ideals and strategies. That this needs to happen is beyond question. Without this meaningful discussions with governments and funding agencies around sustainable ways of supporting the civil society sector in the long term are unlikely to happen.

Local strategies and coordination

Although local government attempts to coordinate community HIV/AIDS responses we found no evidence of a systematic and consistent approach to civil society support. CSOs generally do not report to government except where particularly required to or when particular joint projects are underway.

There is disappointingly little evidence of coordinated local level HIV prevention responses. In one community, after an HIV prevention training programme conducted by CADRE, CSO leaders formed an HIV prevention coalition, to try to launch a concerted HIV prevention drive that involves all key institutions, leaders and sectors of the community. It became clear in this process that CSO leaders are used to coming together around specific events or opportunities only, including training programmes. But it is seldom that they develop strategies beyond meeting the demands of their current commitments. One of the organisation leaders said "*If we want to service the community in this town, we need to come together and say 'this is what we can do separately – this is what we can do together*'".

CBOs do not generally plan together, or align and synchronise their efforts. As one participant commented:

> *"We've got this kind of shotgun approach: everybody just shoots their net into the sky and hopes that they're going to catch as many people as possible. There's nothing about it that's really strategic at all. Our prevention methods need to be streamlined, put together as a sort of coalition, where we meet regularly."(small town CBO leader)*

Forming and taking responsibility for common goals is avoided by organisations struggling to meet their primary commitments to deliver specific services. Even local AIDS councils, health forums and other coordinating bodies show signs of this. The pressing but mundane business of building functionally integrated community services is neglected in favour of time-limited campaigns where coordination and task-delegation are relatively easy to achieve. This is a far cry from the ideal of functional, coordinated community HIV/AIDS responses.

Different CSOs service the same clients, there are duplicated services while other needed services are absent, and in larger communities with greater density of CSOs there is need for better referral systems and need for focusing services where they are needed most. This is particularly true in the area of prevention, where needs are often not immediately evident, as they are, for example, in the case of home-based care.

To secure CSOs must be able to show outputs in terms of numbers of clients/cases and interventions. This creates the context for independent planning around narrowly defined service delivery 'units. This focus sometimes means that CSO leaders are often remarkably uninformed about the activities of other local organisations. In the words of one respondent working under a rural CBO,

> *"I would say the problem is that every organisation has got its own funding and they want to do their own thing, instead of coming together. Now you realise that the information comes differently because one organisation has got its own information and another has got its own information."*

In this context there is a local AIDS council where 'coming together' could happen, because organisations meet, but their meeting is unsatisfactory to all. Although there is widespread support for the idea of coordinated and synchronised local responses to HIV/AIDS, local AIDS councils at municipal level were generally characterised as involving more effort than they are worth.

It appears that that until such councils generate agreed and locally crafted joint strategies the benefit of such forums will not emerge. In one small town there have been two new coordination initiatives launched some years after the local AIDS council was founded. The one is aimed at developing an HIV prevention coalition in the town; initiated by a group of organisations following an HIV-prevention training programme for programme managers led by CADRE. The other is aimed at bringing service providers together in the interest of developing a viable system of community-level palliative care; developed as a pilot project by the national Hospice association. Both of these initiatives were independent of the local AIDS council – although they subsequently have been endorsed by it – and have generated levels of interest and cooperation among local organisations surpassing that generated by local AIDS council activities.

The key difference between these emerging initiatives and the local AIDS council efforts has been the intention of CSOs to develop strategies and action plans based around particular objectives and defined areas of action, and utilising the particular strengths and opportunities of their organisations. To this extent no major new investments are intended. The emerging projects are aimed at 'business as usual' but with greater mutual support and task differentiation; and sharper focus in the areas of HIV prevention and AIDS palliative care. It appears that local AIDS council general networking and coordination, by contrast, is not oriented on a strategy or joint set of objectives and tends to erode the idea of working together; and is seen as involving more work than it is worth.

The CBO leaders who came together to create a prevention coalition agreed about the need to engage members of prevention target populations in prevention programming, to train them as volunteers, and offer ongoing support to them as part of a community initiative. Other ideas mentioned included the pooling of information on high transmission areas, and a more direct focus areas and sub-populations already known to be at risk and as posing a risk, but which have never been directly targeted because of the generic prevention approaches that have been used. In addition the CBO leaders felt that door-to-door prevention education campaigns were more desirable than the mass outreach campaigns, and allowed a greater level of tailoring of HIV prevention responses to specific contexts.

In contexts such as Tanzania where government has assumed responsibility for local coordination, a similar situation prevails. Local coordination agencies serving as link-points between international and government funded projects and local communities, and effectively act as a local version of national AIDS councils. But like the South African counterparts there is little attention paid to strategic planning at local level.

Zimbabwe on the other hand appears to have achieved a high degree of partnership amongst organisations working at multiple levels. These are coordinated through district and provincial AIDS councils, and effective monitoring of responses happens at these levels. There is a measure of coordination from national to village level. CSOs and community leaders have been deliberately and consistently drawn into HIV prevention training and thinking.

This has required specific efforts to translate national strategies into local level strategies. In other countries this work is largely guided by loose conceptions of 'partnership' and multisectoral coordination. The results on the ground are unsatisfactory.

Specific strategies for developing and supporting coordinated HIV prevention responses at local level are needed.

Conclusions

Monitoring and evaluation practices and expectations on the part of funders and government need to develop beyond simple output reporting. For any community-level organisation contribution to community-level outcomes is needed if community-level effects are desired. This requires an entirely different M&E approach, and it requires community-level HIV prevention strategies.

Local coordination needs to be underwritten by local HIV-prevention strategies based on understanding of local HIV transmission dynamics and opportunities of local organisations to work together with shared goals and a joint plan.

6. CONCLUSIONS AND RECOMMENDATIONS

Registered community organisations are in place across South Africa and also the sub-continent, even in rural areas. Although they receive limited, inconsistent funding and support, they generally have committed leadership and are well embedded in communities giving them excellent opportunities to engage the full range of community members and institutions. Their work is supported by large numbers of volunteers hoping to gain experience and some financial compensation, and who are sincerely motivated to serve their communities.

This represents a considerable base of social capital, but these resources have not been adequately harnessed, supported and developed in service of HIV-prevention needs. In South Africa and elsewhere in east and Southern Africa there has been a largely un-strategic and unsystematic approach to supporting localised HIV prevention responses. Policies and strategies in this area remain poorly formulated and inadequately supported.

There has been little systematic investment in local responses from any quarter. What we see at community level is an incomplete mix of interventions, which have emerged as the product of a wide range of criss-crossing influences. These do not reflect what is known scientifically about how HIV prevention behaviour is brought about or supported. It does not encompass the vision of HIV prevention that has developed over the past few years, oriented on the value of understanding and addressing specific modes of transmission in different contexts and working directly to stem these.

The overall result is unsatisfactory although well intentioned and achieved with great determination at community level. From what we see it is likely that efforts to communicate with community members have had limited effects beyond raising awareness and creating a more accommodating environment for people with HIV.

Nonetheless, it is likely that without the civil society efforts described above there would be little HIV/AIDS awareness or care and support at community level. There would likely be higher levels of stigma and greater secrecy around HIV/AIDS.

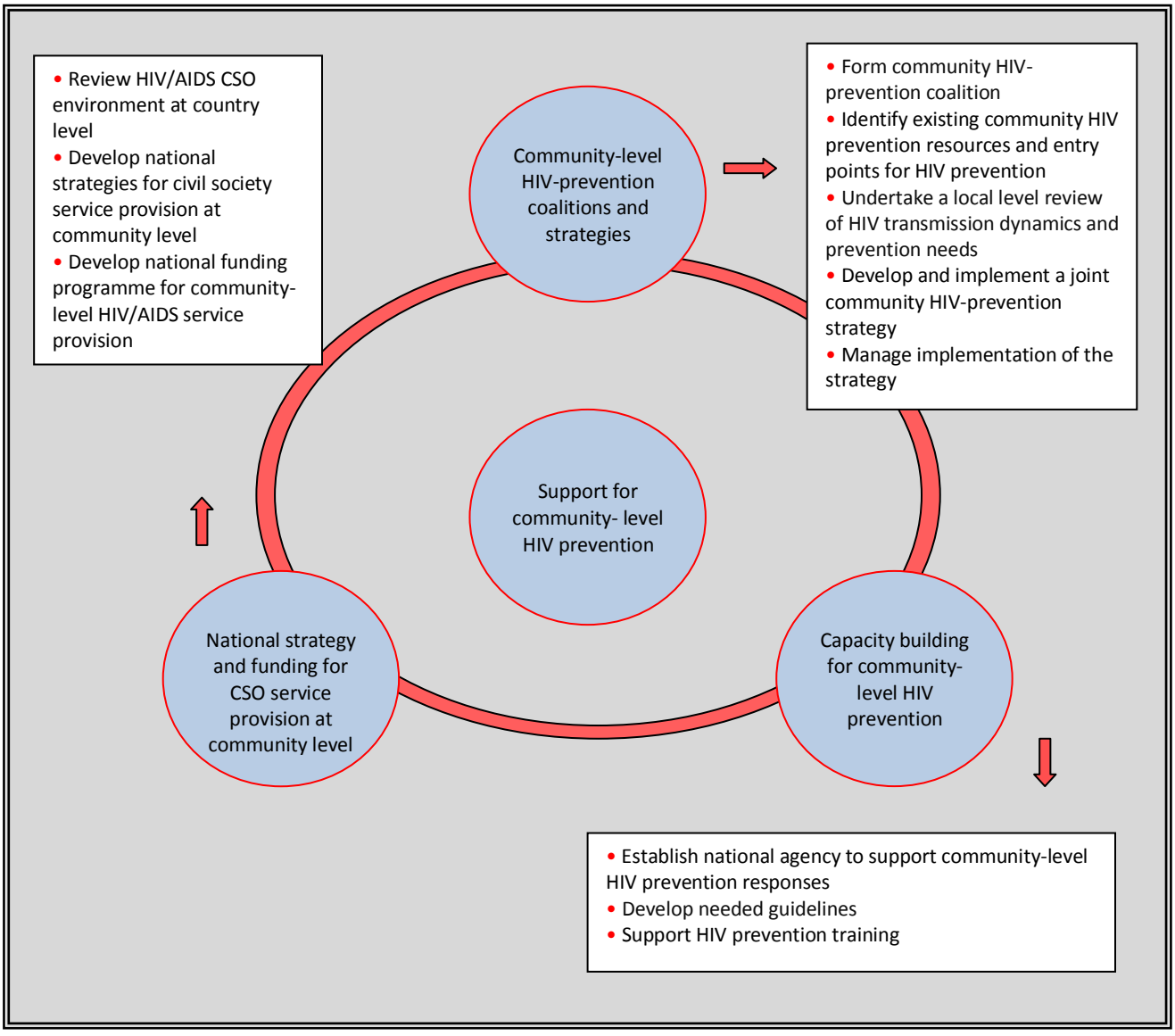
The achievements of these organisations and volunteers have likely gone some way to building what Epstein's (2007) refers to as 'collective efficacy' (see p.9). However, the

area of prevention appears to be a somewhat different case from collective social support which has been shown to be effectively mobilised by community organisations. HIV prevention requires a further and more systematic level of address to achieve its aims: it relies on more than adapting available communication opportunities to address HIV themes. It needs to be more ongoing, better informed by an understanding of how behaviour change is established and supported, and better oriented on changing HIV transmission dynamics at community level.

We now consider what might be done to improve the situation and make good of the assets in place at community level. The goal implicit in these recommendations is to build on the significant gains that have been made by setting in place community-level resources for HIV responses.

Figure 2 below summarises our recommendations for supporting HIV prevention at community level. The approach represents three component areas which must be addressed.

Figure 2: Support for community-level HIV prevention



1. Community-level HIV-prevention coalitions and strategies

Community HIV-prevention programmes must be based on more sensitive HIV surveillance and response analysis. This is necessary to counter the tendency towards generic or 'mass' prevention programmes without careful selection of prevention methods and targeting. There is also a need to move away from event-based and awareness oriented methods towards particular prevention oriented approaches that address particular HIV transmission dynamics.

It is assumed below that the tools and support for the processes described below have been developed. The set of tools needed is outlined in Part 2 below.

Form a local coalition for HIV prevention

The idea of a community-wide HIV prevention strategy which combines the efforts of different organisations working in health and social development must be promoted. A core group of locally active organisations should be formed as a coalition to address HIV-prevention needs and to lead the process of developing a combined strategy.

Identify existing community HIV prevention resources and entry points

Given the largely unstrategic, uncoordinated and piecemeal approaches to prevention that have been found at community level, it is necessary for communities first to take stock of what HIV prevention activities are taking place in the community.

This must include the leaders, organisations, and development initiatives engaged in HIV prevention work, as well as the approaches used and what groups are targeted in HIV prevention programming. All community organisations providing health or social development services should be included in effort to describe what entry points to HIV prevention already exist through their current activities.

This should be done with a view to exploring underutilised opportunities for HIV prevention. It should be guided by understanding of what forms of HIV prevention are appropriate for what modes of transmission. The situation analysis should include services which could be but that are not necessarily involved in HIV prevention, for example family planning and home-based care service providers.

Undertake a local level review of HIV transmission dynamics and prevention needs

As well as understanding the set of available community prevention resources it is important for community level players to take stock of the main drivers of and contexts of HIV infection at community level.

Towards this end there is need for guidance and simple methodologies for taking stock of local HIV infection dynamics. In the absence of available community-level data community organisations may develop understanding of transmission dynamics through knowledge of local HIV/AIDS case loads and known community HIV prevalence hotspots, as well as community level HIV behavioural risks and responses to HIV prevention opportunities (e.g. PMTC services). Much of this information is already known by people working in the field, but needs to be gathered.

Develop and implement a joint community-level HIV prevention strategy

On the basis of the above community based organisations should develop a local HIV

prevention strategy with particular organisations ascribed roles according to their existing focus, strengths and positioning. It is important for the strategy to address the need to target different groups with well selected interventions that are known to work in particular contexts and given particular access opportunities.

This should be adopted, endorsed and jointly pursued with organisations contributing to HIV prevention in ways that are consistent with their other mandates and functions. It should have strong emphasis on linkages between organisations in the interest of HIV-prevention (e.g. linking HIV counselling and testing with HIV support and prevention education).

Manage implementation of the strategy

This strategy should be adopted and implemented by organisations and monitored through existing coordination structures or a core-group formed for the purpose. A national body to support community-level responses, should take responsibility for researching and supporting community prevention strategies and their implementation (see Part 2 below).

2. Capacity building for community-level HIV prevention

Establish national agency to support community-level HIV prevention responses

There is a need for a bridge between community-level action (above) and national level strategy and funding approaches (below).

This requires a national agency representing both civil society and government interests, and focused on supporting implementation of national strategies for community level HIV/AIDS responses, including but not limited to prevention.

This agency should be tasked with developing guidelines, supporting training, monitoring community-level responses, promoting successful models, supporting national HIV/AIDS strategies at community level and strengthening partnerships between civil society service providers and government departments.

Develop needed guidelines for community-level HIV prevention

It is difficult to imagine community-level HIV prevention responses developing more systematically without a set of guidelines to support the development and implementation of joint community-level prevention strategies, as described above. There are already various guidelines for supporting community level HIV/AIDS service provision and organisations, but there is need for guidelines on how to create and implement joint community-level HIV prevention that is sensitive to community transmission dynamics and that optimises existing resources.

There are likely general principles and guidelines that could be applied globally in countries where there is substantial penetration of communities by civil society organisations; but beyond this guidelines would need to be adapted to local conditions and in keeping with national strategies for supporting community-level responses (suggested in Part 3 below).

There is need for the following guidelines to support community-level HIV prevention processes described above:

- Guidelines for forming community prevention coalitions and developing joint HIV prevention strategies.
- Guidelines on what prevention opportunities are best served through what services in order to address specific modes of transmission and sub-population groups. These would need to identify what prevention needs can be addressed through what means (for example, what prevention strategies are appropriate for married couples or HIV-positive people). Guidelines should also identify how the particular prevention value of specific services can be optimised where opportunities exist but are not utilised; for example, family planning, home-based care, orphan and vulnerable children support, and HIV support groups.
- Guidelines for undertaking local level reviews of HIV transmission dynamics and prevention needs, for assessing local HIV prevention coverage and priorities in communities and for developing combined approaches to HIV-prevention through service linkages and referrals.
- Guidelines for managing and monitoring joint HIV-prevention programmes; for example, conducting annual participatory reviews and assessing training and support needs.

Support HIV prevention training

It is remarkable given more than 20 years of evidence of alarming HIV/AIDS impacts, and after mobilisation of masses of volunteers and large numbers of community organisations, that attempts at prevention could be as haphazard and unfocused as they are.

It has been shown above that community HIV/AIDs prevention practitioners lack necessary understanding and expertise and this compromises their achievements. There is little indication of systematic development of prevention training skills.

National efforts must be introduced to support more systematic and standards-based HIV/AIDS training. Training must be oriented on understanding modes of HIV transmission, and how to assess risks in particular communities and specifically address them.

Tertiary institutions in South Africa are gradually seizing the opportunities for offering HIV training to programme managers and counsellors, but systematic training for community-level practitioners in HIV prevention is in critically short supply. At this level both in South Africa and in many other African countries training is largely in the hands of international development organisations, and often oriented on training of project staff or funded organisations in delivery of specific programmes outputs. There is little training in the area of HIV prevention as a speciality area. It is not surprising then that the HIV prevention effects are so limited.

A curriculum approach should be adopted and the suggested national agency should take responsibility for develop a specific skills set for community level health and social development workers. Emphasis should be placed on tailoring prevention approaches suited to particular prevention needs and contexts, based on understanding of what has been learned about what works best for whom. It is also very important to ensure that community HIV/AIDS service providers recognise and pursue HIV prevention opportunities, even when their services are not primarily oriented on prevention. Also , emphasis must be placed on optimising the prevention effectiveness of recognised HIV prevention activities such as HIV counselling and testing.

With national HIV prevention curricula at hand national HIV prevention training programmes should be launched and supported. Many commercial education service providers, indigenous tertiary institutions as well as larger national NGOs are well placed to offer HIV prevention training programmes and this is long overdue. There is likely to be strong interest in undertaking such work were funding to be made available and curricula to be developed.

3. National strategy and funding to support community-level HIV-prevention

Local-level community activity can never be a replacement for large scale, government-led responses to the epidemic, even though community organisations appear to be playing the leading role in certain areas of HIV/AIDS response. Community initiatives, by their very definition, are localised and lack broad 'political economic leverage' (OSAA, 2003). They cannot operate at the scale needed to address the many impacts of the epidemic across society as a whole. Their greatest strength is that they emerge from, reflect and are positioned to engage with local needs and conditions. If national strategies can be developed to more effectively engage and support community-level initiatives there is much to be gained.

Much attention has been paid to the cooperative relationship that emerged between government and civil society in Uganda, where the state effectively contributed to the creation of social capital in society by encouraging CSO activity, by publicly reiterating government commitment to and support of people living with HIV/AIDS, and by mobilising financial support for community institutions (Jamil and Muriisa, 2004). On a much smaller scale, localised networks, such as Children in Distress Network in South Africa (Kelly and Marrengane, 2004), demonstrate that it is possible for state and non-state entities to work together in partnership in a way that enhances overall effectiveness of their efforts.

The CSO sector has a significant head-start in many areas where governments have no notable community footprint or infrastructure for providing social services or launching community-level HIV prevention programmes. In HIV prevention there is much opportunity to build on the foundation of civil society linkages at individual, leadership, inter-organisational and inter-community levels across the country, including remote areas.

Review of the HIV/AIDS CSO environment at country level

Whereas there is good evidence cited in the literature review above, of the successes in civil society HIV/AIDS responses in care, support and impact mitigation, the evidence in prevention is much thinner. This must partly reflect poor progress in prevention generally, but as indicated above, opportunities for HIV prevention at community level have not been systematically or strategically engaged.

There is very little understanding of the size and characteristics of the civil society sector and its contribution to HIV/AIDS responses in general, let alone HIV prevention. There is little vision or long-term roadmap national or international, for how support for civil society should develop and where it should be headed. There is little evidence of attempts to conceptualise models of how CSO responses may survive in the long term. These are important areas for consideration, and in an increasingly competitive international aid environment, have become pressing concerns.

It is a major challenge to ensure that government and civil society efforts complement

and support each other, and it will require specific programmes of support to ensure this; which must begin with recognition of the barely researched civil society HIV/AIDS response sector per country. This must include an appreciation of the scope, scale and coverage of CSOs contributing to HIV/AIDS responses. It must include advocacy organisations, networks, sub-granting mechanisms, training and capacity building organisations, national NGOs and FBOs and community-level organisations.

This should also review policies and strategies for engaging and supporting organisations to provide HIV/AIDS services at community level at national and sub-national levels, and by different government and external agencies.

There are important issues at stake about the long-term role of civil society in HIV/AIDS responses. Development of a stratum of community health workers, who are able to perform a range of functions at community level, including HIV prevention, is one avenue for development which would ultimately diminish the role of civil society service providers. In the interim forms of cooperation need to be devised to support and strengthen HIV/AIDS response opportunities made possible by community organisations. These issues are complex and easy solutions are not likely to be forthcoming in the near future.

Developing a national strategy to support community level HIV/AIDS responses, including prevention, must involve clarifying the following at country level: the forms and types of HIV/AIDS civil society organisations and their strengths and weaknesses; the arrangement of the civil society sector from local to international level; models of cooperation and integration of services at local level; coordination and synchronisation within the civil society sector and with government programmes; provincial, district or local government strategies for engaging civil society organisations; the funding and support environment for civil society responses; incentives and social entrepreneurship in the civil society sector; the relation of civil society agencies and the formal health and social development sectors; and the efficiencies of CBOs versus NGOs which support multiple community programmes.

Develop national strategies for civil society service provision at community level

Concepts of partnership and cooption of civil society representatives onto national and other consultative bodies like country coordinating mechanisms have clearly not achieved much by way of developing the effectiveness of community level service organisations or the civil society sector more generally. Cynical civil society perceptions that government attempts to include them have been tokenistic must be taken seriously. Forays into partnership have been tentative and lacking in commitment and consistency.

Attempts to foster partnerships on the part of national coordinating authorities which lie outside of the mainstream of government and its departments are near meaningless without collaboration and support programmes within government departments at national as well as decentralised levels. This means that it takes more than national AIDS councils to declare intentions of partnership. Governments must also commit to this.

Apart from consultative approaches in developing national and provincial plans there is need for specific government programmes of action to engage civil society service organisations. Standards and expectations regarding government support need to be clarified at a policy level and strategies and guidelines need to be developed. The complementarities of state and the civil society service sectors should be recognised. Principles and frameworks for accountability and mutual support should be made clear

with reference to the different tiers and spheres where state and civil society actors engage.

The role of CSO service providers must be recognised and formally endorsed through a national strategy for engagement of civil society organisations in supporting national HIV/AIDS goals including HIV-prevention. Although the involvement of CSOs is generally recognised by national HIV/AIDS strategies and opportunities for consultation are in place, this generally does not amount to commitments to supporting community level responses in a systematic way. National strategies for civil society organisation engagement must extend from national to local level and must cover the different strata of civil society organisation; but must primarily be oriented on the service delivery end, at community level.

Develop national funding programme for community-level HIV/AIDS prevention

The international funding community and its agencies must recognise that the new funding modalities have compromised the development of the civil society service sector at a crucial time, when consolidation was necessary following a period of rapid expansion.

It is important to re-strategise funding for civil society service organisations in the wake of the 'Three Ones' and the Paris Declaration on aid effectiveness. Even though in the long term it is important to develop community-level health and social welfare services under the umbrella of government, for the foreseeable future more effective ways of optimising and sustaining community-level responses to HIV/AIDS need to be devised.

Country level reviews of funding support for community-level HIV prevention are necessary. How can the efforts of civil society service providers be optimised and developed? What forms of country level sub-granting mechanisms are appropriate for what forms of organisation? What levels and type of funding are required to ensure strengthening and coordination of the civil society sector? How can international funders support civil society service providers without undermining the principles of state support or undermining state sovereignty? How can support for the volunteer base and social capital assets of civil society organisations be invested in while maintaining the delicate balance that sustains the volunteer sector? How can the formal and informal sectors be intermeshed recognising their interdependency; and how should funding work at their interfaces? Country funding strategies must offer practical responses to these difficult questions. State and civil society service organisation relationships differ by country and there is likely no single model for how to promote investment in this range of indigenous civil society actors while remaining committed to supporting national strategic plans and recognising national coordinating authorities.

There is need for a new level of innovation in funding approaches. Community-level HIV prevention responses need collaboration and joint strategies; yet funding is generally only available for single organisations. Grant programmes are needed to support community-level prevention coalitions and joint strategies.

Funding mechanisms must also recognise the need to sustain higher levels of civil society organisation that support community level service provision. These include networks, advocacy support organisations, training and capacity building organisations, sub-granting organisations, national NGOs and FBOs.

7. REFERENCES

Birdsall, K. & Kelly, K. (2005). Community responses to HIV/AIDS in South Africa: Findings from a three-site survey. Johannesburg: DFID/USAID/CADRE.

Birdsall, K., & Kelly, K. (2007). Pioneers, partners, providers: The dynamics of civil society and AIDS funding in Southern Africa. Johannesburg: OSISA/CADRE.

Bourdieu, P. (1985). The forms of capital. In J.G. Richardson. (Ed.), Handbook of theory and research for the sociology of education. New York: Greenwood.

Campbell, C., Nair, Y., Maimane, S., & Sibiya, Z. (2005). Home-based carers: a vital resource for effective ARV roll-out in rural communities? AIDS Bulletin, 14(1), 22-27.

Campbell, C., Williams, B., & Gilgen, D. (2002). Is social capital a useful conceptual tool for exploring community level influences on HIV infection? An exploratory case study from South Africa. AIDS Care, 14(1), 41-54.

Clayton, A., Oakley, P., Taylor, J. (2000). Civil society organisations and service provision. Civil Society and Social Movements Programme Paper 2. Geneva: UNRISD.

Epstein, H. (2007). The invisible cure: Africa, the West and fight against AIDS. London: Penguin Books.

Foster, G. (2002). Understanding community responses to the situation of children affected by AIDS: lessons for external agencies. Geneva: UNRISD (HIV/AIDS and development).

Foster, G. (2004). Study of the response by faith-based organisations to orphans and vulnerable children. New York and Nairobi, World Conference of Religions for Peace / UN Children's Fund.

Fowler, A. (2000). Civil society, NGOs and social development: Changing the name of the game. Geneva: UNRISD.

Fowler, A. (2001). Aid pathologies: Why are they and what can be done about them? Baltimore, Maryland: International Society for Third Sector Research.

Iliffe, J. (2006). The African AIDS epidemic: a history. Oxford: James Currey.

Jamil, I., & Muriisa, R. (2004). Building social capital in Uganda: the role of NGOs in mitigating HIV/AIDS challenges. Paper presented at the conference of the International Society for Third Sector Research, Toronto.

Kawachi, I. (2001). Social capital for health and human development. Development, 44(1), 31-35.

Kelly, K., & Birdsall, K. (2008). Funding for civil society responses to HIV/AIDS in Tanzania: Status, problems, possibilities. Johannesburg: CADRE/ Ford Foundation East Africa Office.

Kelly, K., & Mzizi, T. (2005). The implications of ART for local AIDS care and support programmes. AIDS Bulletin, 14(1), 57-63.

Kelly, K., & Ntlabati, P. (2007). Marketisation of municipal services, daily life and HIV in South Africa, Municipal Services Project Occasional Papers 14. Grahamstown: Municipal Services Project.

Kelly, K., Birdsall, K., Tshose, P., Banati, P., Low-Beer, D. (2005). Community

perspectives on systems effects of HIV/AIDS funding in South Africa. CADRE/Global Fund.

Loffell, J. (2007). Discussion Paper: Use of the statutory foster care system to support long-term kinship care - impact on the social welfare system and the Social work profession. Unpublished. Available from jackiel@worldonline.co.za.

Lönnqvist, L. (2006). The Paris Declaration on Aid Effectiveness: An overview. INTRAC. Source:http://www.intrac.org/resources

Loury, G. (1977). A dynamic theory of racial income differences. In P. Wallace & G. LeMund (Eds.), Women, minorities, and employment. Lexington: Lexington Books.

Low-Beer, D., & Stoneburner, R. (2004). AIDS communication through social networks: Catalyst for behaviour changes in Uganda. African Journal of AIDS Research, 3(1), 1-13.

Mackay, K. (1999). Evaluation capacity development: A diagnostic guide and action framework. ECD Working Paper Series, 6. Washington DC: World Bank Operations Evaluation Department.

Magongo, B., Kelly, K., Parker, W., & Kistner, U. (2004). Development Cooperation Ireland South Africa: non governmental partners in HIV/AIDS - a review. CADRE/DCI. www.cadre.org.za

McIntyre D., Gilson, L., Wadee, H., Thiede, M., & Okarafor, O. (2006). Commercialisation and extreme inequality in health: The policy challenges in South Africa. Journal of International Development, 18(3), 435-446.

Ministry of Health and Social Welfare Swaziland (2005). 9th round of national HIV serosurveillance in women attending antenatal care services at health facilities in Swaziland: survey report. March. Ministry of Health & Social Welfare Swaziland. Mbabane.

MOH & NAC (2008). National AIDS spending assessment for 2005 and 2006. Lusaka: Ministry of Health & National HIV and AIDS/STI/TB Council.

Narayan, D. (1999). Bonds and bridges: social capital and poverty. Washington: World Bank.

Nauta, W. (2004). The changing role of land-sector NGOs in a changing South Africa. Piscataway NJ: Transaction Publishers.

Ndlovu, N. (2005). An exploratory analysis of HIV and AIDS donor funding in South Africa. IDASA Budget Information Service, Budget Brief 155.

Oomman, N. et al. (2007). Following the Funding for HIV/AIDS A Comparative Analysis of the Funding Practices of PEPFAR, the Global Fund and World Bank MAP in Mozambique, Uganda and Zambia. Center for Global Development.

OSAA (2003). Community realities and responses to HIV/AIDS in Sub-Saharan Africa. New York: United Nations Office of the Special Adviser on Africa.

Panos (2003). Missing the message? 20 years of learning from HIV/AIDS. London: Panos Institute.

Pronyk, P. (2002). Social capital and the HIV/AIDS epidemic in rural South Africa. The new magic bullet? PhD thesis. Department of Infectious and Tropical Diseases, London School of London School of Hygiene and Tropical Medicine.

Rangaka, T. (2007). Obstacles on the way for patients to have access to health care in South Africa. Presentation to the South African Human Rights Commission, 31 May 2007.

Rau, B. (2006). The politics of civil society in confronting HIV/AIDS. International Affairs, 82(2), 285-295.

Richter L., Manegold, J., Pather, R. (2004). Family and community interventions for children affected by AIDS. Cape Town: Human Sciences Research Council.

Russell, M., & Schneider, H. (2000). A rapid appraisal of community based HIV/AIDS care and support programmes in South Africa. Durban: Health Systems Trust.

Salamon, L. (1994). The rise of the nonprofit sector. Foreign Affairs, 73(4), 109-122.

Siamwiza, R. (2007). Analysis of Financing for the National HIV and AIDS Response: Civil Society Component. Lusaka: NAC Zambia.

Swilling, M., & Russell, B. (2002). The size and scope of the non-profit sector in South Africa. Durban: Centre for Civil Society.

Teljeur, E. (2002). Response of non-governmental organisations, community-based organisations and communities. In K. Kelly, W. Parker & S. Gelb (Eds.), HIV/AIDS, economics and governance in South Africa: key issues in understanding response. Johannesburg: CADRE/USAID.

Thornton, R. (2003). The Uganda HIV/AIDS success story examined: the role of civil society and linkage to social and economic development. AIDS Mark/USAID.

Versteeg, M. (2006). Decentralised HIV/AIDS response in South Africa: situational analysis. Pretoria: Centre for Municipal Research and Advice.

Wickramasinghe, N. (2005). The idea of civil society in the South: imaginings, transplants, designs. Science and Society, 69(3), 458-486.

Wilkinson, R. (1997). Unhealthy societies: afflictions of inequality. London: Routledge.

APPENDIX – METHODOLOGY

Literature review

A literature review for research focused on community approaches to HIV prevention was conducted. Key themes for the bibliographic search were: 1) community and local level responses to HIV prevention; 2) civil society engagement in HIV prevention.

Data gathering

Sources used included original data collected specifically for the purposes of the study, as well as secondary analysis of data available in CADRE's database. During the period of the research CADRE also used its ongoing community-level engagements and HIV prevention communication training work as opportunities to gather data for the study.

The following data gathering procedures were conducted.

NGO and CBO perspectives

The following focus group discussions were conducted in English and Xhosa as appropriate. These were recorded and transcribed, with translation where necessary.

- A focus group discussion with eleven people representing organisations engaged in HIV prevention projects in a small town of the Eastern Cape Province of South Africa.
- A focus group discussion with ten people representing organisations engaged in HIV prevention projects in rural towns of the Eastern Cape Province of South Africa.
- A focus group discussion with nine people representing organisations engaged in HIV prevention in a city in the Eastern Cape Province of South Africa.

The range of NGOs and CBOs represented included: an HIV counselling and testing centre; an HIV support centre; a hospice association; a child welfare society; a tertiary education institution; a rural arts and development association; a family and marriage support society; a rural development NGO; a schools HIV prevention organisation; and an NGO focused on sexual and reproductive health. A representative of a government department responsible for promoting HIV prevention in education was also present.

Rural community perspectives

For this component three focus groups were conducted in Ngqeleni, a deep rural area of the Eastern Cape Province of South Africa characterised by high levels of unemployment, strong reliance on remittances and government grants for subsistence, and high levels of migrancy, especially among men who seek work in the cities.

The interviews and focus groups were conducted in Xhosa, and translated into English in the process of transcription. The following data collection procedures were conducted.

- A focus group discussion with a team of eight young men, ranging from seventeen to twenty-five years of age and involved in or exposed to a community-level HIV prevention programme. Few men in this group had finished high school, and the majority were unemployed.
- A focus group discussion with a team of eight unemployed male and female volunteers ranging in age from twenty-five to thirty-four years of age, working at community level in an HIV prevention project supported by an NGO.

- A focus group discussion with nine home-based carers from different villages providing home care to people afflicted by HIV/AIDS and support to their families. The carers received compensation for their work in the form of stipends from the provincial Department of Social Welfare.
- A focus group discussion with nine members of an HIV-positive support group, most of whom were unemployed.
- An interview with a home-based care leader employed by an NGO.
- An interview with an HIV prevention project team leader employed by an NGO located in a rural area of the Eastern Cape Province of South Africa.

HIV prevention practitioners

During the period of this study CADRE was engaged in developing an HIV prevention training programme, oriented on HIV prevention needs at the local level. The core activity of the training involved presentations of HIV prevention modules on a range of topics, followed by exercises and facilitated discussions around key prevention issues.

The three trainings involved a total of 12 days of intensive discussion of HIV prevention challenges and opportunities at community level. Since this training took place during the period of the study it played a significant role in sharpening our research questions and also provided new material for analysis.

A total of 65 individuals were involved and were selected to participate in the trainings as representatives of civil society organisations involved in HIV/AIDS prevention. The training programmes was conducted in South Africa, Tanzania and Zimbabwe and the participants represent forty eight civil society organisations representing CBOs, NGOs and national civil society network organisations. Three international NGOs also participated in the training, as well as five representatives of government departments involved in supporting HIV/AIDS responses at community level.

The focus of these organisations included: networking and support for HIV-positive people; support for vulnerable children; home-based and palliative care; prevention education and training; coordination of responses; HIV counselling and testing (HTC); prevention of mother to child transmission (PMTCT); HIV in the context of disability; sub-granting to civil society organisations; CSO capacity building; and community-media focused organisations.

Other primary data sources

During the course of the study CADRE was involved in a number of other research projects and evaluation studies that provided opportunity to address the study questions. These included:

- An evaluation of a faith-based care and support initiative oriented on protecting and nurturing children and young-people directly affected by HIV/AIDS, spanning the most underdeveloped region of South Africa as well as urban informal settlements in the largest metropolitan area of the country.
- An ongoing study of communication and social mobilisation for supporting prevention of mother-to-child transmission of HIV in five sub-districts across South Africa. This involved consultations with community members, local leaders and government officials about obstacles and opportunities for PMTCT.
- An ongoing study of cultural perspectives on male medical circumcision.

Secondary sources of data

The following secondary sources of data were used.

- Data from a six-country (Lesotho, Malawi, Mozambique, Namibia, Swaziland, Zambia) study conducted by CADRE focused on the changing dynamics of civil society funding and responses to HIV/AIDS (Birdsall and Kelly, 2007). This involved a survey of 439 CSOs organisations. It also involved more than 50 interviews with donors, government HIV/AIDS agencies and civil society leaders; and case studies of local responses to HIV/AIDS and the support they receive in all six countries.
- Our second source is a study of the funding environment for civil society responses to HIV/AIDS in Tanzania (Kelly & Birdsall, 2008) and a case study of a Tanzanian community organisation's struggle to respond to HIV/AIDS (Kelly, 2008).

Data analysis

For analysis of the primary material gathered specifically for this report an initial set of analytic codes were developed following a meeting of the research team to discuss themes evident in the data.

Transcribed data were imported into nVivo8 – a qualitative data management programme – then coded according to an initial analytical framework. As the coding proceeded sub-codes emerged and were added to the coding framework.

The data clustered under each code were further categorised through sub-headings This material was then written up in a narrative format. In this process the final structure for presenting the findings was determined and the findings were further shaped in developing sub-categories.

The secondary sources of data were mostly used to interrogate and qualify findings in writing the report and as sources in the review of literature.

Limitations and validity of study

This is an exploratory study aimed at teasing out the challenges and opportunities for supporting efficient and effective HIV responses at the community level. Given the varied data sources used, the study is not representative of a particular setting or country. Attempts have been made to describe the factors which have shaped community-level HIV prevention responses. Findings and commonalities at this level have allowed some generalisation across settings.

The findings and recommendations have been shaped by perspectives and data from a wide range of contexts both within South Africa and from other East and Southern African countries that have generalised HIV epidemics. This has helped to strengthen the generalisability of the findings and recommendations.